

Fetal and Infant Mortality Review:



A Guide for Home Interviewers

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Shaefer J. When an Infant Dies: Cross-Cultural Expressions of Grief and Loss. NFIMR Bulletin. Washington, DC: American College of Obstetricians and Gynecologists, July 1999

FIMR: A tool communities can use to address issues related to health disparities in infant outcomes. NFIMR Bulletin. Washington, DC: American College of Obstetricians and Gynecologists, Spring 2001

National Fetal and Infant Mortality Review Program Data Abstraction Forms. The maternal interview. Washington, DC: American College of Obstetricians and Gynecologists, April 1996

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CHAPTER 1

The Fetal and Infant Mortality Review (FIMR) Process

Introduction

First developed in the late 1980s, the Fetal and Infant Mortality Review (FIMR) program is a dynamic community process aimed at improving the health and well-being of women, infants, and families. Although the basic process is the same in most FIMR programs, the specific operations are localized. Sponsoring agencies vary and include city and county health departments, local hospitals, regional perinatal centers, and community-based maternal and child health coalitions.

The home interview is a unique and special part of all FIMR programs. The interview reveals the mother's perspective on her infant's death. It provides a window into her life and sheds light on the factors associated with her baby's death. The interview provides community-specific information that vital statistics cannot. The mother's input has proven to be crucial for changing the community for the better.

The committed individuals who conduct home interviews play an essential role in the FIMR process. For more than a decade, FIMR home interviewers have recorded the mother's story of loss and carried it back to the community. The caring and compassion that FIMR interviewers offer bereaved families transcend cultural, socioeconomic, racial, and geographic boundaries. Interviewers have been welcomed into thousands of homes across the country. In addition to listening and recording the mother's story, interviewers have also provided much-needed referrals to health and human services resources.

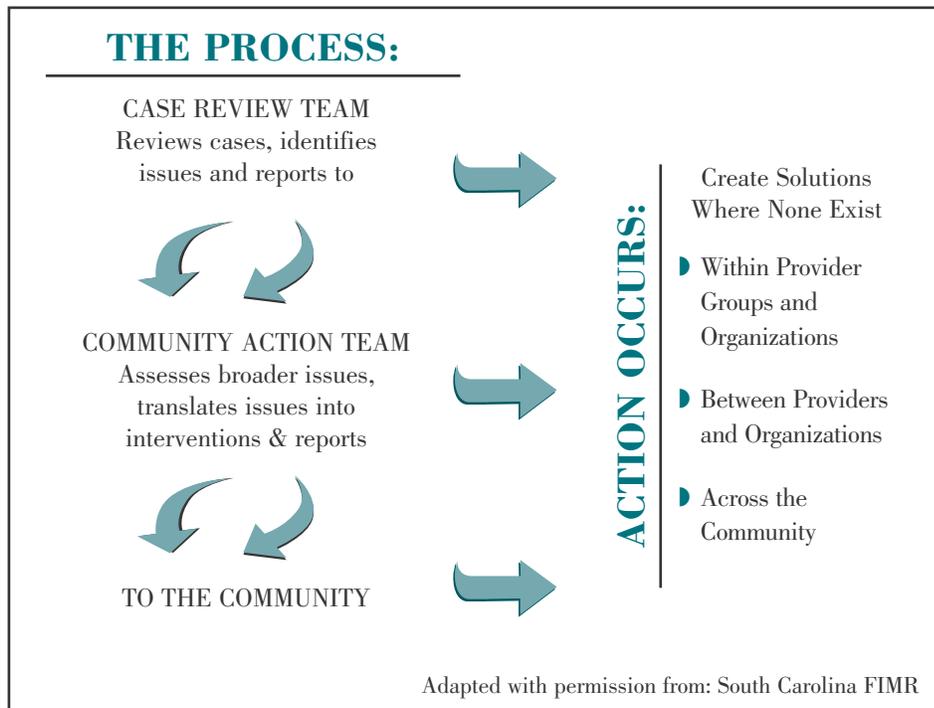
The purpose of this manual is to help prepare the new interviewer for the key FIMR role of interviewing grieving mothers. Over time, guidelines for FIMR interview techniques have evolved and improved. This publication incorporates the most current information on best practices to assist the FIMR home visitor.

This manual is not intended to take the place of formal home visitor training such as that provided by other local FIMR program staff, state Title V agencies, local or state professionals with expertise in sudden infant death syndrome (SIDS), or national bereavement programs. Instead, the manual should be used as a teaching tool in these formal training sessions.





Figure 1.
The FIMR process.



For more in-depth information about the FIMR methodology, see Buckley KA, Koontz AM, Casey S. Fetal and infant mortality review manual: a guide for communities. Washington, DC. American College of Obstetricians and Gynecologists, 1998. This document is available free of charge by writing NFIMR, 409 12th Street, Washington, DC 20024.

Why Examine Fetal and Infant Deaths?

Fetal and infant mortality are unique among health outcomes. They are key indicators of a community's social, economic, civic, and environmental well-being, as well as its health. It is often said that healthy communities nurture healthy women, infants, and families.

Although the quality and amount of prenatal and pediatric health care affects fetal and infant outcomes, the success of the connections among local service systems on behalf of the family is also an important dynamic. Outcomes are affected by access to care, socioeconomic conditions, and the balance between family resources and stressors.

Vital statistics provide important information about the rates and causes of fetal and infant deaths, but not about many of the factors contributing to those deaths. Statistics alone do not suggest strategies to address problems at the



local level. This is the role and unique value of FIMR. FIMR complements quantitative, population-based statistics by providing qualitative information about the conditions affecting fetal and infant outcomes within a given community. The FIMR process facilitates the development of meaningful solutions to local problems. It guides efforts to improve services for mothers at greatest risk for poor outcomes.

As one FIMR team epidemiologist explained (1):

“The Infant Mortality Review Program permits us to go well beyond the analysis of vital records information, to reveal the underlying experiences, attitudes and medical histories of pregnant and parenting women and the offspring they have lost. Held up for inspection and review by a multidisciplinary Community Review Team committed to improving perinatal health outcomes in the community, this information provides a ‘window’ into the maternal and child health systems in the community.”

Goal of the FIMR Process

The goal of FIMR is to enhance the health and well-being of women, infants, and families. FIMR does this by improving the community resources and service programs available to them. Through FIMR, key members of the community come together to review information about individual fetal and infant deaths. The reviewers identify the factors related to these deaths and decide whether these are isolated cases or system-wide problems that need to be addressed. They also develop recommendations for change and help put those changes into action. Figure 1 illustrates the FIMR process.

FIMR objectives are:

- To identify the social, economic, cultural, safety, and health issues that emerge from review of death among fetuses and infants
- To work with community members to target and maintain the positive aspects of programs serving families
- To work with community members to identify interventions to target and eliminate the negative factors that are found through the reviews

“Maternal interviews give a voice to the disenfranchised in my community, those without clout or power. FIMR provides a rare opportunity for the ‘providers’ in a community to hear from the ‘consumers.’”

**-Patt Young, FIMR Interviewer,
Alameda/Contra Costa Counties, CA**



- To help carry out those interventions to eliminate negative factors found in the reviews
- To assess the progress made

The FIMR Home Interview

“Maternal interviews give a voice to the disenfranchised in my community, those without clout or power. FIMR provides a rare opportunity for the ‘providers’ in a community to hear from the ‘consumers.’”

–Patt Young, FIMR Interviewer,
Alameda/Contra Costa Counties, CA

The maternal interview is the cornerstone of FIMR because it provides the mother’s perspective of her baby’s death. FIMR is unique because it allows the mother to describe her experiences in her own words.

The home interviewer conveys the mother’s story to the FIMR review team. Thus, the voice of each bereaved parent reaches the community at large. Team members report that the home interview provides some of the most valuable information in the review. They are better able to gauge the extent to which services and community resources are available, accessible, and culturally appropriate. They can more readily identify areas of deficiency or inequality in service delivery systems. Finally, the team can begin to address these problems more effectively.

The FIMR interview process can provide solace to the grieving mother. It affords an opportunity to offer emotional support as well as referring mothers to needed services.

However, the FIMR home interviewer does not assume the role of a professional grief counselor. FIMR interviewers are encouraged to compile a comprehensive list of culturally appropriate community resources, support groups, and educational materials. The interviewer provides referrals to trained bereavement counselors, local SIDS professionals, or peer support programs. In this way, the FIMR home interviewer works with the family to develop an ongoing support program as needed.

In summary, the purposes of the FIMR maternal interview are:

- To learn about the mother’s experiences before and during pregnancy

- 
- To learn about events during the infant’s life and around the time of death
 - To identify community assets and deficits that affected the mother’s life during the pregnancy, birth, and death of her infant
 - To accurately summarize and convey the mother’s story of her encounters with local service systems and her loss to the community through the FIMR case review
 - To assess the family’s needs and provide culturally appropriate health and human referrals as needed
 - To facilitate the bereavement process and provide appropriate referrals

The FIMR Interviewer

The FIMR interview provides a great deal of information about the fetal or infant death and also challenges the interviewer’s ability to support a mother in her grief and bereavement. In general, a mother may not always be looking for all of the answers about why her baby died but appreciates the opportunity to talk about the life and death of her baby.

Training in the FIMR process, which includes interviewing and active listening techniques, cultural competence, and bereavement support, is necessary before the first interview is scheduled. It is also essential to have knowledge of community resources and the ability to make a wide variety of referrals. The interviewer must be familiar with the cultural and ethnic groups in the community and be comfortable with home visiting. On a personal level, a commitment and recognition of the importance of the FIMR mission enables the interviewer to continue this challenging work with bereaved mothers.

The FIMR interviewer must also be committed to maintaining the strictest confidentiality. Case information must be kept anonymous. Information about the mother, her caregivers, or institutions that provided services to her or her baby cannot be discussed with colleagues. Locating mothers without divulging the purpose of the visit to others can be challenging, but it is important to establish trust with the mother and protect her privacy.

“In general, a mother may not always be looking for all of the answers about why her baby died but appreciates the opportunity to talk about the life and death of her baby.”



“The FIMR Interviewer offers a unique contribution to the FIMR review team by becoming the voice of the mother. She speaks for the mother to the rest of the community.”

Mothers relate well to an interviewer who is empathetic, mature, warm, sincere, nonjudgmental, and interested. Although mothers and family members might not remember everything the home interviewer said, they will certainly recall whether or not she displays a caring attitude and offers comfort. By simply taking the time to sit with the mother, the interviewer can demonstrate caring. She can express condolences, explain what is known about the cause of death, and respond to family needs associated with the death. Mothers and families will take solace in this kindness and remember that visitor for a lifetime. A successful FIMR interviewer is one who (2):

- Understands her or his own feelings regarding death
- Recognizes that expressions of grief and loss are culturally influenced
- Is comfortable with mothers who have experienced a fetal or infant loss
- Recognizes that fetal or infant death is a momentous and often overwhelming event in the mother’s life
- Reassures the mother that the interviewer is there to provide a community service, not to criticize the mother’s actions or behavior
- Believes all mothers will benefit from the visit
- Feels the visit is not an intrusion but an opportunity to gather information and provide culturally appropriate support and reassurance
- Realizes that most mothers want to talk about their babies and their losses
- Takes direction from the mother on the length, scope, and general course of the visit

The FIMR Interviewer offers a unique contribution to the FIMR review team by becoming the voice of the mother. She speaks for the mother to the rest of the community. This is both a demanding and rewarding role. The FIMR interviewer performs an invaluable service not only to affected families but also to the entire community.

CHAPTER 2

Conducting the FIMR Interview

NFIMR promotes the premise that the ideal location for the interview is the home because it sheds light on the physical environment of the mother and infant. Interviewing bereaved mothers in the home is one of the most challenging aspects of providing maternal-child health services. The interviewer encourages mothers to talk about one of the most painful losses a person can experience—the death of a child. Listening to the mother talk about her feelings may awaken painful memories or provoke fearful thoughts about the interviewer’s own children. Despite these challenges, interviewers can derive personal and professional satisfaction by successfully supporting the mother while completing the interview.

Interview Preparation

Preparation for the interview is essential for success. The first step is to determine who should be interviewed (usually the mother) and then to locate that individual. The initial contact sets the tone for subsequent meetings. The following sections explain how to decide who should be interviewed and offer suggestions for the initial contact and interview. Also included are advice about how to handle a refusal to participate and how to administer the interview tool, as well as useful tables on safety and preparation. Figure 2 provides details on preparing for the FIMR interview.

Who Should Be Interviewed? Typically, the mother is interviewed because she is the primary caregiver of the infant. The mother is in a unique position to talk about the pregnancy, labor, delivery, and care of the infant. She can also provide important information about her level of satisfaction with the care she and the baby received.

If the mother is deceased or is not the infant’s primary caregiver, the individual who is the primary caregiver is interviewed. The father, grandmother, aunt, other family member, or foster mother may have assumed this role. The caregiver may not have all the details but should be able to contribute information about the health and well-being of the infant.

The interviewer asks highly personal and sensitive questions, and the mother may not wish to answer them in front of anyone

(continued on page 10)





Figure 2.

Home Interviewers: The Art of Being Prepared

Why devote so much time and energy to being prepared? This initial “investment” pays off in the most important way. Once the details have been tended to, we are free to give our full attention to the interview and the mother being interviewed. We can listen sympathetically with as few distractions as possible and can better handle those that do come up. The preparations can be divided into three categories: Physical, Mental, and Professional.

Physical Preparation

◆ Checklist for briefcase:

- Sharpened pencils, pens
- Pad
- Note cards
- Business cards
- Permission/release forms
- Interview forms
- Pregnancy calculator wheel
- Calendars (previous and current years)

◆ Clip or mark unneeded pages of questionnaire in advance.

◆ Keep car in good repair and have plenty of gas.

◆ Dress appropriately and comfortably, not flashy.

◆ Lighten your load—avoid pocketbooks. “Pocket-organize” items such as cell phones, beepers, and keys. Remember to turn off cell phones and beepers during the interview.

◆ Bring tissues.

◆ Bring items for children to play with, such as a basket of toys, coloring books and crayons, etc.

Mental Preparation

◆ Know your own physical limitations.

◆ Stay focused on the objectives of program. Remind yourself why you are going there.

◆ Put superfluous thoughts from your mind and prepare to give full attention to this mother.



- ▶ En route, review items such as how to pronounce the family's name, the child's name, and other information you were given by the mother during your telephone call.
- ▶ Avoid making assumptions about the mother's frame of mind; it may be different when you arrive.

Professional Preparation

- ▶ Research the best route to your destination, following field safety and security guidelines en route and after arrival.
- ▶ Be on time. Call if you are going to be delayed. A good response is: "It's a new area to me. I should be there at _____, but give me a few minutes."
- ▶ Be flexible concerning the mother's condition.
- ▶ Be patient; don't expect the mother to always be logical or objective.
- ▶ Be nonjudgmental. Be ready to listen. Want to listen.
- ▶ Allow yourself to have feelings.
- ▶ Have a ready list of community resources and support groups. (Update this list periodically; keep current on subjects through sources such as the library, the Internet, etc.)

Other Hints for During and After the Interview

- ▶ Develop ways to ensure that you have recorded the information accurately, without asking the mother to repeat herself.
- ▶ Allow the mother to digress; one memory often triggers another.
- ▶ Avoid sharing your own values.
- ▶ If the mother is an adolescent: Being aware of the developmental tasks and needs of adolescents can help us to accept, without judgment, behaviors and attitudes we might find unacceptable in adult parents.
- ▶ Exhibit sympathy, respect, and genuineness.
- ▶ On the way home, replay the interview in your mind. Something may emerge that is worth noting on a handy note pad or on a microcassette tape recorder.

Adapted from: Wood J. FIMR Interviewer. Healthy Start Coalition of Hillsborough County, FL



(continued from page 7)

else. Therefore, most FIMR programs interview the mother privately and separately from other members of the family.

Occasionally, a mother and father may request to be interviewed together. Often they can support each other during this process. Fathers can contribute information and reap the same cathartic benefit experienced by mothers. On the other hand, on rare occasions, an abusive partner may not want the baby's mother to talk with the interviewer alone and may insist on being present. For this reason, questions concerning spouse abuse are generally omitted when both parents are interviewed at the same time.

The mother's apparent need for support should be tempered by the interviewer's judgment about including other family members during the interview. The interviewer should be alert to the mother's cues about whom she would like to join her in the interview or if she prefers to be alone. The interviewer must safeguard the mother's privacy while obtaining information.

One mother who did not get prenatal care until late in the third trimester told her grandmother that she went to the clinic in the first trimester. The grandmother was going to be present during the interview, but the mother did not want her to know the truth.

This mother had a dilemma that caused her considerable stress. The interviewer should try to be alert to a mother's unexpressed needs and concerns about the interview.

Maintaining Confidentiality. The process of locating mothers also requires sensitivity and attention to maintaining strict confidentiality. The mother may not want other family members to know about her experience. For example, she may have miscarried during the pregnancy, or before the infant's death, the infant may have been taken into protective custody or placed in foster care.

If the mother is not at home, the interviewer should not mention the FIMR process by name or describe the purpose of the interview to any other party without the mother's consent. Communications with other family members, residents, or neighbors should include only general information. For the same reason, envelopes mailed to mothers or business cards left on the door should not include the name "Fetal and Infant Mortality Review Program."



When Interviewing Is Not Recommended. Home interviewers need to be especially sensitive and usually do not contact mothers around holidays, the anniversary of the infant’s birth or death, Mother’s Day, and other special times. Some mothers appreciate the opportunity to discuss their baby at such times, but many others do not want to be disturbed in their grief. The interviewer can simply ask the mother what is a good time for her. However, it is not appropriate for the first contact with the mother to take place immediately before a holiday or other sensitive times. In addition to supporting the mother, the interviewer also needs to recognize that her or his own emotional availability may be limited during the holidays. Although these are good rules for restricting home visiting around certain sensitive times, the interviewer should still try to be open to exceptions if the mother requests help or would like to be interviewed.

Patt Young, FIMR Interviewer, Alameda/Contra Costa Counties, CA, describes a mother who called requesting to be interviewed during the Christmas holiday. The mother was very distressed about her baby’s death. The mother had thrown her Christmas tree out into the back yard. After the interview she wanted to bring the tree back into the house. The interview process had been very helpful and supportive. She had other children and felt she could now celebrate the holiday festivities.

Because of overriding ethical and/or legal concerns, FIMR programs strictly avoid interviewing mothers in certain cases, such as:

- Mothers hospitalized for psychiatric conditions
- Mothers who are in litigation with providers or institutions because of the circumstances of the infant’s death
- Mothers who are under investigation or imprisoned for complicity in the death of their infant. FIMR programs have interviewed mothers who are incarcerated for other crimes (e.g., theft, bad check writing, etc.); these mothers also have important stories to tell.

Reporting Child Abuse. All states have child abuse reporting laws that require physicians, nurses, social workers, teachers, and other health and human service professionals to report suspected child abuse and neglect. These statutes confer immunity from civil

“Home interviewers need to be especially sensitive and usually do not contact mothers around holidays, the anniversary of the infant’s birth or death, Mother’s Day, and other special times.”



and criminal prosecution upon those reporting. If the interviewer suspects abuse of the deceased infant or observes abuse or neglect of surviving children in the home, she must report it. Each state has a specific reporting system. Therefore, the interviewer should check with the FIMR coordinator well in advance of the first interview to determine the proper reporting process.

Interview Consent Form. A legally valid consent form is required from the mother and any other family member who agrees to participate in the home interview. The consent form should clearly specify the purpose of the interview, definitions of terms, steps taken to protect confidentiality, potential benefits and risks for the participant, and agreement to participate (Figure 3). In some states, the consent also states that any information on child abuse will be reported.

The informed consent should also include a statement indicating that the mother understands the information on the form and that any questions she may have had were answered. The interviewer should check with the FIMR program coordinator well in advance of the first interview to be sure that:

- The agency sponsoring FIMR has developed a specific FIMR interview consent form that is ready to use
- The form covers all relevant provisions in federal and state statutes
- State and/or local legal authorities have reviewed and formally approved the form

Locating Mothers. Finding mothers after an infant loss can be challenging. Some mothers move after an infant death because the home holds such powerful memories and sad reminders of their baby. Some move because of poverty, unemployment, or homelessness and do not leave behind any forwarding information. Others may have been just passing through the area at the time of the loss and have since moved on. A few may have given false contact information.

Although the death certificate is a good way to identify cases, it does not always have the most useful or accurate information for locating mothers. Vital records usually have the mother's address but not the phone number. For this reason, it may be necessary to search other sources for valid contact information.



Figure 3.
FIMR Home Interview Consent Form

Purpose of the Interview

(*NAME any county Department of Health*) is conducting a Fetal and Infant Mortality Review (FIMR) Program. The purpose of this program is to identify factors associated with fetal and infant deaths and to find ways to help families such as yours in the future. To achieve these goals, we wish to interview mothers (or other family members) who have recently experienced the loss of a fetus or infant.

You have been asked to participate in the program because you have recently lost a fetus or infant. If you voluntarily agree to participate, a trained interviewer from the (*NAME any county Department of Health*) will ask you a series of questions about the death of your baby and about your pregnancy, health, family, and use of health care and social services. The interview will take place in your home at a time that is convenient for you. The interview will take about one hour. Although participation in this program may not benefit you or your family directly, it may help to prevent other families in the future from losing their baby.

Description of Potential Risk

Talking about the death of your baby may prove difficult for you. The interviewer is not a professional counselor but, if you wish, will give you the names of professional people who can help you deal with the loss of your baby. If, during the course of the interview, you feel you do not want to continue, you may ask the interviewer to stop the interview at any time. There is no expected risk of injury for participants in this study.

Description of Potential Benefits

Participation in the interview may be a positive experience for you. You may find that talking about the death of your baby can

help ease the pain of your loss. In addition, the information you provide to this program may help prevent the loss of a baby to future families.

Alternative Procedures

The alternative to participating in this interview is to choose not to participate at all.

Confidentiality of Records

All information that identifies you, your family, or your health providers will be removed before the interview questionnaire is reviewed. All Fetal and Infant Mortality Review staff and consultants have signed an oath of confidentiality. Therefore, confidentiality will be protected to the full extent permitted by law.

Compensation

You will not be paid for participating in the interview.

Voluntary Participation

Your participation in this program is completely voluntary and you may refuse to answer any questions that you do not wish to answer. You are also free to end the interview at any time without any consequences to you or your family.

Questions

If you have questions concerning the interview or the Fetal and Infant Mortality Review Program, you may call (*Name of Contact Person*), collect, at the (*NAME any county Department of Health*) at (*Contact Telephone Number*).

Consent

I have read this form and understand the purpose and conditions for participation in the Fetal and Infant Mortality Review Program. I hereby consent to participate in the program. I agree to participate in an interview. I understand that all information obtained from the interview will be strictly confidential, and that neither my name, my baby’s name, nor the name of anyone else in my family will appear in any publications or reports or be given to anyone else.

Print Name: _____

Signature: _____

Date: _____

Interviewer’s Name: _____

Interviewer’s Signature: _____

Date: _____

Adapted from: Alameda/Contra Costa Perinatal Network FIMR Program, Oakland, CA



“Connecting with families shortly after the death has enabled us to provide much-needed support while completing the interview at a later date. This direct referral process has cut down the number of hours we spend on case-finding activities.”

**—Dawn Dailey, RN, MSN,
Contra Costa County Health Services
FIMR Coordinator**

The most successful interviewers use multiple sources to find the mother’s address. They may locate new addresses or telephone numbers by contacting post offices or telephone, electric, or gas companies. Whatever the protocol, the interviewer cannot give details about why she wants to locate the mother. The interviewer can explain that she is from the County Health Department and needs to contact the mother but must not give the specific reason. It is also important not to specify the reason for the contact when attempting to locate the mother through relatives, friends, or neighbors. Confidentiality should always be maintained.

Each program should develop guidelines on how comprehensive an attempt the interviewers should make to locate the mother. Generally, if the mother has moved out of the county or state, the attempt should cease. Depending on the program, the case could still be abstracted and presented, noting that the mother moved out of the area.

Dawn Dailey, RN, MSN, Contra Costa County Health Services FIMR Coordinator reports on her program’s success in locating families.

“Our greatest success in connecting with families for the FIMR interview has been through developing close relationships with our hospitals and local agencies. We have established a mechanism to receive referrals directly from the hospitals in addition to receiving vital registry birth/death certificates. Connecting with families shortly after the death has enabled us to provide much-needed support while completing the interview at a later date. This direct referral process has cut down the number of hours we spend on case-finding activities. We usually visit families an average of two visits. To establish relationships with the hospitals and local providers, we developed a publication with our FIMR Task Force, “Guidelines Following a Pregnancy Loss or Infant Death.” It contains valuable follow-up guidelines for providers and includes a section on making an FIMR referral. We also organized short trainings to orient agencies to FIMR.”

When the interviewer finds the address, she should try to get as much information as possible, including the following:

- ZIP code
- North and south orientation of streets
- Entire street name (e.g., Elm Court, not just Elm) or county rural route number
- Type of structure (condominium, apartment, single-family home, etc.)



- Color and type of building material (brick, wood)
- Nearest bus, subway, or metro stop
- Landmarks or major cross streets near the home

A detailed local map and a compass on the dashboard are important tools to take along on the trip to the home interview. A cell phone is also essential for personal safety and for calling 911 in case of a family emergency in homes without a telephone.

Best Time to Contact. There are two models for conducting the home interview: the early contact approach and the standard approach. In both approaches, FIMR obtains written permission for the interview and makes referrals to community resources.

In the early contact approach, the interviewer talks to the mother 2–3 days after the death. The interviewer visits the mother as soon as possible after the loss to offer support, reassurance, and any needed referrals. Information on the funeral and burial will also be needed. The formal interview is done at a later date. After the interview is completed, the FIMR interviewer may maintain periodic contact with the mother by telephone, letter, or home visit. However, the interviewer does not take on responsibility for the mother’s continuing care. The mother is referred for case management, if indicated.

In the standard approach, the interviewer typically contacts the mother 1–3 months after the death. Mothers are sent a standard FIMR letter and brochure offering condolence and informing them of the FIMR program. Mothers are then contacted by phone or home visit to explain the process and request an interview. In this situation, the interviewer tends to have less contact with the mother after the interview. However, the interviewer provides needed referrals for community and/or bereavement services.

Initial Contact. The initial contact may be made by letter or phone call. In some communities, a home visit is the most appropriate first contact. Many FIMR interviewers say that it is important to send out letters within 3 months of the loss. After 3 months, it becomes much more difficult to successfully contact the mother.

Some programs mail a letter (for an example, see Figure 4), whereas others send a condolence card. Confidentiality is ensured by omitting the name of the FIMR program from the return address.

Questions Mothers May Ask.

Following are sample questions and answers that mothers may ask about the interview. The interviewer might want to develop sample questions and responses that relate to a new FIMR program’s particular circumstances (3).

Question:

How did you learn my name?

Sample Answer:

All infant deaths are routinely reported to the County Health Department by the Vital Statistics office.

Question:

How did you learn my phone number?

Sample answer:

Your number was found by
(a) Calling information, or
(b) Looking in the local directory

Question:

How did you find my unlisted phone number?

Sample Answer:

Hospitals in our community routinely forward copies of records of infants who die to the health department. We obtained it from those records.

Question:

What’s in this for me?

Sample Answer:

It may help you to talk about the loss. Health and medical care are important concerns for us all. The information you provide may help to provide information about changes we need to make. Also, I may be able to help arrange for health or social services that can assist you and your family.

Question:

How do I really know you represent the County Health?

Sample Answer:

I will show you my official identification badge. You can also call this county number to check. I will be glad to send you information by mail if you prefer.

Question:

Why is the interview worthwhile?

Sample answer:

The information obtained will be used to look at prenatal and baby care and health habits to find ways to help families and prevent future deaths from occurring.



“The caller should try to establish an atmosphere of trust by using a gentle, reassuring approach, starting with general, non-threatening questions . . .”

In some cases, programs send a letter with a self-addressed reply note that allows the mother to indicate whether she wishes to be contacted. Whatever method is used, the language in the letter should be simple, consistent, and written at about a sixth-grade reading level. Bereaved mothers often are not able to concentrate or struggle through long letters.

A call or visit should be made no more than 1 week after the letter is sent. Telephoning can impose some limitations on communication because the interviewer may miss nonverbal cues. However, it can be useful for making an initial contact in a timely manner. The person who makes the initial contact should be sure to review any background information on the family and infant before making the call. Telephone etiquette requires that the interviewer identify herself or himself and state the name of the program before proceeding with the conversation.

The caller should try to establish an atmosphere of trust by using a gentle, reassuring approach, starting with general, non-threatening questions and progressing cautiously to the more sensitive, potentially painful ones.

■ An example would be *“Hello, Ms. _____. My name is _____. I am from _____ (agency) and am calling to follow up on a letter that I sent you last week..”*

People who are hurting are especially sensitive to voice tone and the manner in which information is presented. Personal names should be used to increase the level of trust.

■ Following the above statement, the caller may say, *“Ms. _____, I was so very sorry to hear about the loss of _____ (baby’s name, if known, or your daughter/son/baby).”*

The mother’s response will determine the interviewer’s next response. There may be a period of silence.

■ The interviewer may then continue, *“My letter was about an important community program that I am involved with. The purpose is to learn about each baby’s death in our area and to find ways to help families such as yours in the future.”*

If no questions are voiced, the caller should clarify the interview process and set a date and time to meet with the mother.

■ *“I would like to make an appointment to visit you and hear your story. What would be convenient for you?”*



Figure 4.
Sample Letter to the Family from the FIMR Program

Dear *<NAME>*:

On behalf of the *<NAME OF LOCAL FIMR PROGRAM GROUP>* please accept our heartfelt condolences and deepest sympathy to you and your family upon the loss of your child. The loss of any infant in our community affects us all; part of our future is lost. We feel that it is worthwhile to do everything possible to learn from these tragedies so that, if at all possible, they might be prevented from happening again.

Understandably, this a very difficult time for you and your family. However, I would like to invite you to participate in an important program to better understand why these tragedies happen and to learn how future losses may be prevented. We recognize that some infant deaths are not preventable. By talking with each family in our community who has experienced the tragedy of infant loss, we will learn from their experience. Perhaps we can then become more informed and helpful to families in the future.

Should you choose to participate in this program, *<CONTACT NAME>* from the *<NAME OF LOCAL FIMR PROGRAM GROUP>* will schedule a meeting with you, preferably in the privacy and comfort of your own home or another place, if you choose. This visit will give you an opportunity to talk about your pregnancy, your personal experiences surrounding the loss of your child, and the services that you received and the ones you may have wished for that were not available. Your participation in this program is completely voluntary, and all information gathered is completely confidential; your name and the name of your child will never be identified.

I hope you will choose to take part in this program. By doing so, you may help improve the services and care for all mothers and babies in *<NAME OF COUNTY OR AREA SERVED>*. Thank you for your consideration. *<CONTACT NAME>* will contact you within the next few weeks.

Sincerely,

<NAME OF DIRECTOR OR PROGRAM COORDINATOR>

<TITLE>

Adapted from: Western North Carolina FIMR Program, Asheville, NC



Before hanging up, the interviewer may let the mother know about educational materials that are available.

- *“I have informational materials that I can bring for you. I also have information for children, grandparents, and fathers. Is there any specific information that may be helpful to you?”*

The interviewer should leave a telephone number where she can be reached so the mother can change the appointment if she wishes.

Refusals. Not all mothers want to participate in FIMR. Although about 10% of mothers are typically lost to follow-up, successful interviewers usually interview about 60–70% of the mothers they do contact. It may be useful to have an ongoing, weekly dialogue with the FIMR coordinator to address problems and evaluate success in tracking and interviewing.

Because of the sensitive nature of the home interview, however, it is important to be mindful of the needs of the mother when trying to encourage her to participate. When a mother says that she does not wish to participate, the interviewer may try the following (4):

- Explain that the information gathered from the interview will be used to look at prenatal and child health services and community resources to find ways to help families such as theirs in the future.
- Ask the mother to at least begin the interview and answer one or two sample questions on a trial basis. Let her know she is free to stop the interview at any time. Also, she can refuse to answer any question that she does not like or feels is too sensitive. Many times, this approach encourages the mother to provide most of the information needed for the interview.
- Ask permission to call back in a month or two to revisit the mother’s decision not to participate.

Some mothers have reported that it was just too hard to go through the interview even though they had said they would. They needed more time. Therefore, the interviewer may occasionally arrive at a scheduled appointment to find no one at home. If this happens, the interviewer should follow up with a respectful and concerned telephone call. Often the second appointment will result in a successful interview.

The interviewer should be prepared to deal with well-meaning but misguided relatives. Sometimes family members will meet the



interviewer at the door and say the mother is not home because they believe the interview will upset her. The interviewer may leave, only to be called later by the mother, asking where the interviewer was and why she missed the interview. Sometimes a park bench or a coffee shop makes a good alternate interview site.

Best Interview Site. NFIMR promotes the premise that the ideal location for the interview is the home because it sheds light on the physical environment of the mother and infant. Visiting the family's home gives the interviewer a unique opportunity to meet the mother in a natural context. The interviewer can gain insights into her home life and a better understanding of the family.

However, it is important to be safe in any home visiting situation. To ensure safety, each and every FIMR home visitor must be constantly vigilant and aware of the surroundings. No matter what part of the county, the setting (rural, suburban, or city), or the socioeconomic status of the neighborhood, the interviewer should follow the same safety precautions. Safety suggestions are listed in Appendix A.

Other locations may be offered as options as long as privacy and confidentiality can be maintained. Interviews have been conducted by telephone and at the health department office, coffee shops, parks, playgrounds, and the mother's place of business. The time of the interview should be as flexible as possible. The interviewer should be able to schedule interviews during the evening or weekend for mothers who cannot be available during regular business hours.

Working with Interpreters (5)

Helping a mother who is coping with fetal or infant loss is difficult enough when both the mother and the home interviewer speak the same language. When a language barrier limits communication, the home visit can be a significant challenge. Interpreters can help bridge this gap if they are carefully chosen and trained. This section recommends a few basic guidelines for choosing, training, and working with interpreters.

Choosing an Interpreter. Not everyone who speaks a particular language can interpret in that language. Translating from one language to another is not as easy as it appears. Many English words and phrases have no exact counterpart in another language. Some FIMR interview questions may require longer explanations to clarify the ideas they represent. In addition, fetal and infant loss is a



“Culture, educational background, and experience can all play an important role in how an individual understands and responds to the words the interviewer speaks and the questions she asks. For these reasons, interpreters must have a good understanding of both languages and cultures.”

sensitive and emotional issue. These factors add to the difficulty of interviewing and communicating in a different language. Thus, the interviewer should plan ahead and be aware that an interview involving an interpreter will take longer than the usual interview.

The FIMR home interview contains open-ended as well as closed-ended questions. The interview begins with an open-ended question about the mother’s experiences. The interviewer has the special task of working with the interpreter after the home visit to create an accurate summary of the mother’s comments for the FIMR case review team. The interviewer also must help educate the team members about cultural traditions of different groups in the community.

Culture, educational background, and experience can all play an important role in how an individual understands and responds to the words the interviewer speaks and the questions she asks. For these reasons, interpreters must have a good understanding of both languages and cultures. In general, most bereaved mothers respond to and feel more comfortable with female interpreters. The interviewer should try to follow these fundamental guidelines for choosing an effective interpreter:

- Well before the first interview, study the cultural makeup of the community. Work with the FIMR coordinator to ascertain the need for interpreters and to identify people who can act as interpreters. Look for native speakers who also speak English well.
- Develop a list of several potential interpreters, but try to use the same one as often as possible. This will help develop a good working relationship.
- Look for a mature native speaker that has lived and worked in the country for a period of time. She will probably have a better understanding of American culture as well as her own.
- Interview the potential interpreter. Assess her or his knowledge of fetal and infant loss and her ability to understand and empathize with the bereaved parents.
- Never use children as interpreters. The issues surrounding the FIMR interview are too sensitive for them to handle.
- If, after all other options have been exhausted, an adult family member is the only option for interpreting, take the time to prepare her or him by following the instructions outlined below in preparing the interpreter.



Prepare the interpreter for the job at hand

- Train the interpreter(s). First assess the interpreter's understanding of the causes of fetal and infant loss and correct any misunderstandings. Then explain the purpose of the interview and what the interpreter is expected to do.
- Role-play the explanation of the informed consent and the FIMR home interview with the interpreter before going on a home visit. Encourage the interpreter to report if she needs to rephrase a question in order to be understood or if any question might be culturally inappropriate.
- Seek help. If using an interpreter is a new experience, turn to more experienced peers for guidance.

When an interpreter is needed

- If the interviewer arrives at a home and finds that the mother does not speak English, it is better to set up another appointment when an interpreter can be present.

During the interview

- Speak to and make eye contact with the mother, not the interpreter. Never assume that the mother or other family members who are present do not understand what is said. Many people understand English better than they speak it.
- Speaking loudly will not help the mother understand. Speak to the mother in a normal tone of voice.
- Do not make assumptions. Do not presuppose that the mother is uneducated because she does not speak English. Ask the mother what she knows before beginning the interview, just as with an English-speaking family. Adjust the FIMR interview and bereavement support to her level.
- Observe body language. Watch for signs of discomfort, confusion, and other emotions or reactions. Do not hesitate to ask the interpreter's opinion to understand reactions from the mother.
- Be genuine. The interviewer should not be so overly concerned about offending the mother's cultural traditions or lifestyles that she fails to provide support and caring. All people respond positively to respect. The interviewer can demonstrate caring by being kind, attentive, and sensitive to the mother's needs.



- Communicate with the interpreter. The interviewer should feel free to ask the interpreter questions about what is being said, how the interview is being translated.
- Debrief the interpreter after the interview. The interpreter will need support to deal with her or his own feelings about grief and loss (see the section “Self-Care for the FIMR Interviewer” later in this manual)) and to assess her emotional response to the mother and the interview.

Become actively involved

- Learn proper greetings and expressions of sympathy in the mother’s language. This will convey respect for the mother and demonstrate a willingness to learn about the community.
- Learn about customs and traditions regarding birth, illness, fetal and infant death, burial rites, and other important beliefs and values for each different cultural group in the community.
- Over time, make a commitment to learn other basic words and sentences of the mother’s language. Become familiar with any special terminology used by bereaved mothers. Even though an interviewer might not speak well enough to communicate directly, the more she understands, the greater the chance to understand the interpreter-mother interchange.
- Have educational materials available about fetal and infant loss in languages used in the community and offer them to families as needed.
- Make a commitment to update and expand a list of culturally appropriate referral resources, such as pastoral care, community centers, and funeral homes that can provide follow-up services to culturally diverse families.

Ethical Considerations

Interviewing mothers about the loss of their child or pregnancy can present ethical dilemmas. Grieving mothers are vulnerable, and extra care must be taken to be sure that no harm is done to them. Mothers must be able to give informed consent and should not be manipulated into participating in any way. They should never be coerced or pressured. Neither should they be offered money or any other kind of inducement that might make them feel obligated to



participate. However, tokens of appreciation, such as a book of stamps, a plant, or coupons to a local grocery store are sometimes given after the interview.

The NFIMR Interview Tool

During the early years, a variety of home interview tools emerged from the FIMR programs. A comprehensive instrument was developed by NFIMR and modified in 1996 with input from local programs throughout the country. Most FIMR programs currently use this tool or a modified version. The benefits of using the NFIMR home interview tool include national compatibility, comprehensive format, and ease of modification for individual program needs. It is free to local FIMR programs and ready for data entry with NFIMR software.

The interview tool can be presented in various ways according to the preference of the interviewer and mother. Most interviewers find it helpful to organize interview materials and resources in advance. Many interviewers punch holes in the interview tool and place it in a binder to facilitate writing and page turning. The interviewer should make sure she knows where everything is so that things can be found quickly. Being prepared helps the interviewer focus on the mother's responses and conduct the interview in an organized fashion. The interviewer's organization and composed manner also help assure the mother that she is respected and that her input is valued.

A very experienced interviewer who has conducted as many as 75–100 home visits may do the survey without the forms and fill them out later after the interview. With this method, the interviewer will have memorized an outline of the standardized questions. However, she still must take notes to help recall answers when writing up the information.

Some interviewers have reported doing the interview over the telephone at the mother's request. Although it would be difficult to complete the entire interview form by phone, certain key questions could be asked. Barriers to this method include the inability to obtain written consent to conduct the interview and difficulty assessing the mother's living situation and need for community referrals. Whatever interview method is used, the mother's requests should be accommodated whenever possible.



“The interviewer should review the NFIMR Home Interview Tool carefully before making the home visit.”

Sections of the Interview Tool. The NFIMR Home Interview Tool is divided into sections or topics. A comparable Spanish version is also available. One additional section is used if the infant was discharged home from the hospital. The sections are:

- Beginning the Interview (see pages 27–29)
- Prenatal Care
- Nutrition, Weight Gain, and Health Habits
- Delivery of Baby
- Other Babies
- Information on Mother
- Information on Father
- Living Situation
- Life Changes and Social Support
- Baby’s Health At Home: Supplement

These sections consist mainly of short-answer, fill-in-the-blank questions. Each ends with an open-ended question that gives the mother an opportunity to add anything else she wants to share.

The interviewer should review the NFIMR Home Interview Tool carefully before making the home visit. She should be familiar with the content of each section and should remove pages or sections she knows in advance will not be needed. For example, if the baby did not come home, the “Baby’s Health at Home: Supplement” will not be used.

Information about each section follows.

Part A: Prenatal Care. This section appears to be very long because of the wide ranges of potential responses. In addition, each question includes the category “Other” with space for the interviewer to write in the response. This section also has the most questions that might be skipped over, depending on the mother’s situation. For example, questions 14–19, which ask about alternative sites of prenatal care, would be skipped if the mother had only one site of care.

Part B: Nutrition, Weight Gain, and Health Habits. This section is used to assess knowledge and resources for nutritional care. Questions 9–14, which address the mother’s ability to buy food, should be asked at the interviewer’s discretion.



Questions 15–24 assess the mother’s use of tobacco, alcohol, and other substances. These questions should be asked in a neutral, non-accusatory manner. For mothers that have admitted to tobacco, alcohol, or drug use, the questions are a sensitive way to assess usage levels and ask whether she was able to reduce her intake during the pregnancy. Many mothers who admit to drug use in the FIMR interview are almost always willing to accept referrals for treatment. Referrals for substance abuse treatment should be offered, but usually at a time other than the interview. If a mother reports never smoking, drinking alcohol, or using drugs in her life, questions 23 and 24 may be the only ones needed.

Part C: Delivery of Baby. This is a brief introductory section beginning the discussion on delivery of the infant. If there was a fetal death, only questions 1–7 are asked and the interviewer skips to the next section, part D.

Part D: Other Babies. This section gives the mother an opportunity to talk about her other children and/or losses. If this was the first baby and the first pregnancy, the interviewer moves to question 6.

Part E: Information on Mother. This section asks for general demographic information about the mother. It helps give insight into her education, skills, and employment. If she is not employed, only questions 1–8 are asked.

Part F: Information on Father. This is used to collect general demographic information about the baby’s father. It includes questions about the mother and father’s relationship and the emotional support they give each other. If the father is participating in the interview, the interviewer omits questions 8–11 on spousal abuse.

Part G: Living Situation. This section asks about living conditions during the pregnancy and before the loss. Some questions address worries about money for food and rent.

Part H: Life Changes and Social Support. This section assesses the mother’s life stressors before and after the recent pregnancy. It allows the interviewer to focus on the mother’s available social support and resources. If the father of the baby is present for this section, the interviewer omits questions 2 and 3 on spousal abuse.

The mother’s answers to questions 5–8 provide insight into where she is in her grief work. They present an opportunity to share infor-



**“Give me an ear and I will
give you a voice.”**

—Kahlil Gibran, *Sand and Foam*

mation on expressions of grief, community referrals, and educational bereavement support materials. Questions 9 and 10 are important because they ask for the mother’s input about what needs to be done in the community to help other women and families experiencing a fetal or infant loss.

Baby’s Health at Home: Supplement. This section is used only if the baby came home from the hospital after birth. The questions assess the infant care education and access to medical services provided by the community. Some of the answers may already have been given in the course of the interview. Because questions about the baby’s home life and death can be especially painful for the mother, these should be approached thoughtfully and with sensitivity.

Interview Length. The interview takes as long as necessary for the mother to tell her story. Some mothers have a lot to say and as many questions to ask as the home interviewer. The home interviewer may be the first and only person the mother has had an opportunity to talk with about her loss. The interviewer must try to balance the need to get answers to the questionnaire with the mother’s need to expound on her experiences. Both are important. In most cases, the whole process takes about 1-3 hours and may be done in one or two visits.

The Interview

Give me an ear and I will give you a voice.

—Kahlil Gibran, *Sand and Foam*

The interviewer has a unique opportunity to learn about this mother and family in their own environment. She should be prepared to adapt to the life, space, and activities of the family. The way the mother receives the interviewer and the interviewer’s response will influence the tone of communication.

Because many mothers are sensitive to any hint of criticism about their lifestyles, health habits, or parenting skills, it is important to avoid making negative comments. The interviewer should have an overall attitude that is neutral and should avoid expressions of disapproval or disappointment. On the other hand, the interviewer can reassure the mother about whatever is known to be true and posi-

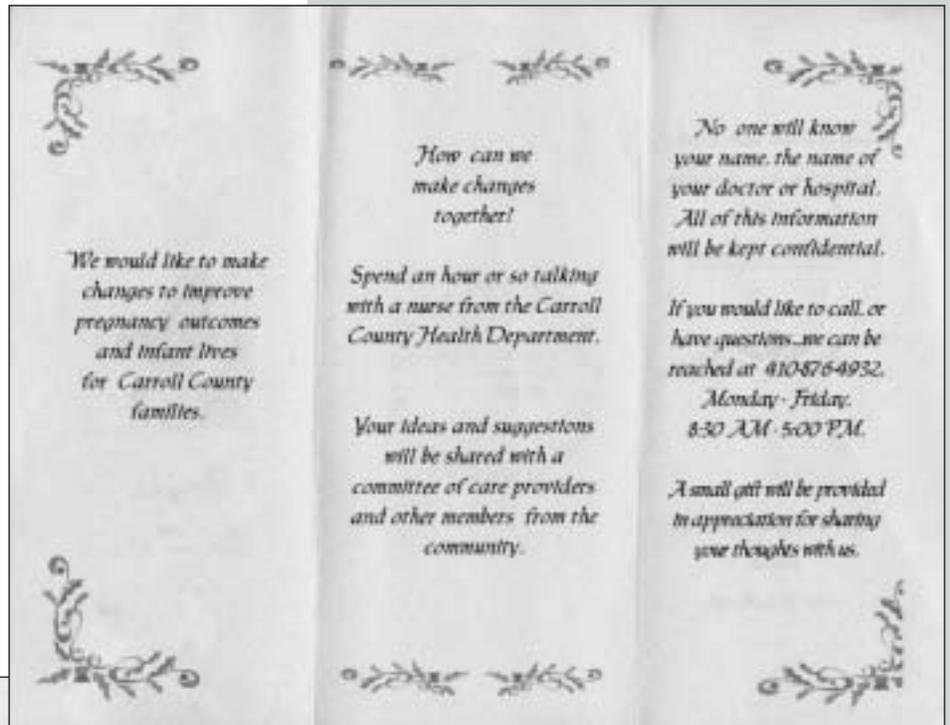


tive about the case (e.g., that the mother did everything that she could, that the medical care for her baby was the best, etc.).

Initial Greeting. When greeting the mother, the interviewer should introduce herself, tell the mother which agency she is from, and show her official identification. The interviewer should then use the infant’s name, if it is known, and offer the mother condolences about her baby’s death. The mother should be fully informed about the FIMR program and interview and the significance of her involvement. If the program has FIMR pamphlets or brochures, this information should be shared at this time. Before beginning the interview, the interviewer should inform the mother that she may refuse to answer any questions or may terminate the interview at any time without fear of losing any current or future services.

The Consent. At an appropriate time after the initial introductions and condolences have been made, the interviewer should review the consent form with the mother. The interviewer should witness and co-sign the consent form to document that the mother has been informed of these issues and understands them. The interviewer should leave a blank copy or a carbon copy of the consent form with the mother and should keep the original signed consent form.

Beginning the FIMR Interview. Once a comfortable atmosphere has been created, the best way to begin the interview is to ask the mother to describe in her own words the events leading up to the death of



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“Sometimes home interviewers say that they feel powerless to take away the mother’s grief, but it is not possible to do this. It is possible, however, for the interviewer to facilitate healthy grieving through her own actions . . . “

her infant. The interviewer should continue to call the infant by his or her name, if it is known. In this first section of the interview, the mother tells her story in her own words. This may be the most sensitive and emotionally laden part of the interview.

The following open-ended questions from the NFIMR interview are a good way to start the discussion:

- “Tell me what happened to [baby’s name].”
- “How was the baby’s death explained to you?”
- “Thinking back on the experience, what would make things better for you?”
- “What do you think needs to be done to help other families who experience the death of an infant?”

The interviewer should use active listening skills while the mother gives her answers to these questions. It is important to respond to the mother’s story with compassion. The interviewer should not take notes but should record these opening remarks after the visit. The interviewer may jot down a few key reminder words as the mother’s story unfolds. The pace of the interview should be relaxed and not rushed. It is to the interviewer’s advantage to allow the mother to discuss her experience before asking any direct questions.

Helpful responses include listening, touching (such as holding a hand or even giving a hug), and saying the baby’s name. Crying can also be appropriate if the interviewer’s sorrow does not interfere with comforting the family. Simple phrases can convey support, such as:

“I’m sad for you.”

“How are you doing with all of this?”

“This must be hard for you.”

“What can I do for you?”

“I’m here and I want to listen.”

Sometimes home interviewers say that they feel powerless to take away the mother’s grief, but it is not possible to do this. It is possible, however, for the interviewer to facilitate healthy grieving through her own actions—expressing sadness about the death, offering condolences, using the child’s name, encouraging parents to talk to each other, and advocating for family support services.



The mother may start to talk about the loss before the interviewer asks. She may want to share pictures of the baby, mementos, or copies of the birth or death certificates. If the mother does not volunteer to share these keepsakes, the interviewer can gently ask her whether she wants to share them. The mother should be encouraged to share both positive and painful memories. It is important to remain sensitive to the mother's need to expand upon or move away from a particular event that generates strong feelings. The interviewer should give her time to recall details and to relate her experiences in her own words.

While the mother is telling her story, it is possible to probe for other items from the questionnaire. After the mother has told her story, the interviewer can begin to ask interview questions not previously discussed. It is a challenge for the interviewer to gently direct the mother's comments while giving her the opportunity to discuss her feelings and concerns. Throughout the interview, the mother should have the time to express her feelings and to have her questions answered.

If the mother becomes sidetracked and is not addressing any relevant content area, gentle redirection is suggested. For example, if the mother is complaining repeatedly about a friend's insensitive response, the interviewer can acknowledge how difficult and disappointing that must have been and ask what happened next or direct the conversation to one of the FIMR-specific content areas.

Father's Participation. Sometimes the father wants to be included in the interview process. The interviewer should be alert to the mother's cues about her desire to have the father present for the entire interview. One option is to give both parents the opportunity to discuss the loss of their infant. Often, it is enough to let the father share his feelings about the experience. The remainder of the interview can then be completed with the mother.

If the father wants to be included, the interviewer can offer to interview him separately, as follows:

"I am delighted that you want to participate in the interview. While part of the information pertains to feelings and experiences your partner had during pregnancy, there are special sections that you can answer as well. I will interview you after I record the information from your partner."



Understanding Grief

The death of your baby is certainly one of the most painful experiences you will ever have.

Be patient with yourself. Grief has lots of ups and downs. It lasts much longer than most people realize.

There is no right way to deal with death. Everyone grieves in his or her own way — one person may be angry, another may be quiet and sad, while others might hide their feelings and seem not to care.

Crying and wanting to talk about your feelings are normal and can help you feel better. Share with others and allow your tears to come.

Friends and neighbors want to help you but sometimes don't know how. Tell them when you need to be held or hugged and talk with them about your baby so they know it's O.K. to do that.

Children need to know the truth. Don't tell them that the baby "went to sleep" or "went away on a long trip." That might make them afraid to go to sleep or go away from home. Be sure they understand that the baby's death was not their fault.

Decide what to do about your baby's clothes and toys when you're ready, not when others tell you to.

Guilt and anger are natural, normal reactions to grief. Again, it's best to share these feelings in ways that are healthy and not harmful to others. Holding your feelings inside will usually make you more depressed.

The interviewer will then have to decide which questions in the FIMR interview the father will be able to answer (e.g., Part F: Information on Father, questions 1–7; Part G: Living Situation, questions 1–13; or Part H: Life Changes, questions 9–10).

When the father is present during the interview, the interviewer must be careful to avoid any questions about spousal abuse.

Completing the Interview. When the interview is completed, the interviewer should thank the mother for her participation

and give her the opportunity to relate any feelings she may have about the interview process. If not done previously during the interview, the interviewer should discuss normal grief reactions (e.g., the inability to sleep or eat properly, difficulties in interpersonal relationships, aching arms, hearing the baby cry, longing to hold the baby, reactions to other babies, seeing babies on television).

Information about local support groups, such as Compassionate Friends, or SIDS and hospital-based support groups, should be left in case the mother desires services after the interview. The interviewer must be knowledgeable about and prepared to link



Ask questions to find out everything you can about what happened to your baby, but remember that sometimes there just are no answers.

Learn to forgive yourself when you have thoughts of "if only."

You may be tempted to use alcohol or prescription drugs to dull the pain, but this will only delay the grief process. To move through the pain of grief and loss, it must be faced head on.

Grief over the loss of a baby is emotionally, mentally, and physically exhausting. Some common physical reactions are not wanting to eat or eating too much, problems sleeping, sexual difficulties, and even aching arms. A balanced diet, rest, and some exercise are very important for you during this time.

Remember, healing from the pain of grief is a slow but certain process.



"Take heart, dear friend, and don't forget . . . the sunrise never failed us yet."





parents to culturally appropriate pastoral care or other referrals for continued counseling, if indicated. (Resource information is provided at the end of this publication under “Resources for FIMR Home Visitors.”)

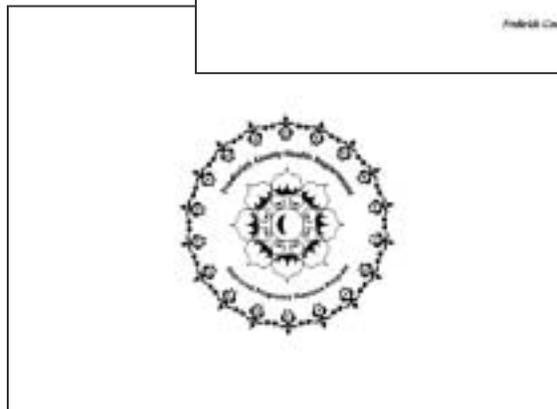
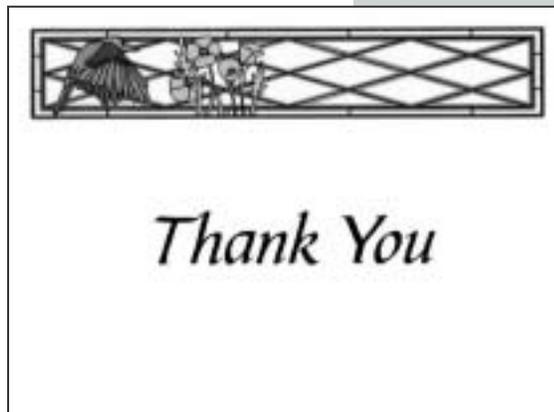
If health or safety issues are apparent (e.g., no heat in winter, no food available, or critical health problems in the family), the interviewer should address them at this time. Other referrals that the mother may want or need should be provided. For example, mothers may need information about child development services, WIC, or fuel assistance programs.

The interviewer should be sure to give the mother a telephone number where she can be reached. No mother should be left in an emotionally escalated state. If the mother is very upset, the interviewer should sit with her and acknowledge how difficult it is when a baby dies. The interviewer may offer to call a friend or relative to sit with her, if she prefers. If during the visit there is a health or psychiatric emergency, the interviewer should call 911.

Mother’s Evaluation of Interview. Before leaving the home, the interviewer may want to give the mother an evaluation form so the mother can comment anonymously on the interview process (Figure 5). A self-addressed, stamped envelope should be included for her convenience.

FIMR interviewers say that best practices always include sending a letter expressing appreciation and condolences a few days after the interview. An evaluation form could also be included with the condolence card.

“The interviewer must be knowledgeable about and prepared to link parents to culturally appropriate pastoral care or other referrals for continued counseling, if indicated.”



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Figure 5.
Evaluation of the FIMR home interview.

COMMENTS	AGREE STRONGLY	AGREE SOMEWHAT	DISAGREE SOMEWHAT	DISAGREE STRONGLY
The interview gave me an opportunity to openly share my feelings.				
It was beneficial for me to answer questions about my loss.				
I felt that I could help other bereaved families by participating in the program.				
I gained some insight about my loss through participation in the program.				

Other Comments:

Thank you so much!!!

Adapted from: Cooke A. The experience of bereavement research: stressful or therapeutic?
Death Studies. 1995, Volume 19, pp 157-170.



Protecting Confidential Information After the Interview

Maintaining the mother's confidentiality after the interview is completed is of utmost importance. Interviewers can discuss what they learned during the interview only with the FIMR coordinator. They cannot discuss the interview content with other colleagues, even in debriefing sessions. Relatives or friends who might otherwise hear some details about work cannot be told anything about the home interview session.

Finally, the interviewer must remember the importance of protecting both paper and electronic copies of all information.

Interviewers should never write family, provider, or institutional identifiers on the interview form, but only the number assigned to the case. In the field, the interviewer should be careful not to leave completed forms out in a car where they could be seen or stolen. Forms must be locked in the trunk until they can be transferred to the locked files within the office.

In the office, completed forms should always be stored in a locked file. If the interview is being summarized or entered into a computer database and the transcriber must leave, even briefly, the record must be locked up and the computer screen should be closed.

Computer systems for entering or summarizing maternal interview information should be secured with a password. It is essential that no one learn the information obtained from this mother.

At the end of the case review meeting, FIMR staff should destroy all possible paper or electronic links that connect a case to a family. Finally, after the review, and if the law allows, the paper copy of the actual home interview form should be shredded.

CHAPTER 3

Understanding the Grief Experience

“And can it be that in a world so full and busy, the loss of one weak creature makes a void in any heart, so wide and deep that nothing but the width and depth of vast eternity can fill it up!”

—Charles Dickens, *Dombey and Son*

Grief is a normal, natural response to a significant loss (6). Grieving the death of a loved one transcends family, societal, and cultural boundaries. Grieving the death of a child is a life-long process of learning to live without the physical presence of the child.

Grief is a complex topic. There are many aspects of the grief experience. The literature offers a variety of theories to explain the process of bereavement and healing. These theories provide a foundation for understanding the mother’s grief work. The term work is used because the process of grieving the death of a child is such a difficult endeavor.

Worden (7) describes four tasks of mourning. The first task is to accept the reality of the loss. Initially, the mother knows that her baby has died, but she is not ready to face the reality of that loss. Once she accepts the reality, she becomes immersed in the second task, which is to experience the pain of grief. The bereaved must experience the pain to get through it. One strategy to tolerate the intense pain is to designate times to focus on the loss. The third task is to adjust to a life without the baby. For mothers, this may require a significant change in their daily activities. For example, if the mother stayed at home to care for the baby, she will be faced with empty days that she will need to fill in other ways. The final task is to reinvest emotional energy. Reinvesting emotional energy does not mean that a mother forgets her baby. Many mothers who have lost a child want to continue their role as a mother. In many cases, a mother may become pregnant again. This pregnancy offers her the opportunity to be a successful parent with a live child.

Worden’s tasks describe the work of the grieving mother as she comes to terms with her baby’s death. Neither grief nor its tasks have a specific time line. Parents usually describe the first year as being the most difficult as they experience each “first,” such as the first birthday and the first holiday without the child.

A mother delivered a baby at 26 weeks. Her son survived only 1 week due to a severe cardiac defect. She accepted her baby’s death





“A mother grieves as an individual but also within the context of the family. It is important to know the members of her family, their ages, sexes, and roles in the family.”

and returned to work. When the baby’s due date arrived, she found herself in emotional turmoil. She thought she had been doing well, but when this date arrived, it felt as though the death had just occurred.

There may be fluid movement among the tasks. As anniversaries arrive, mothers may find themselves reliving their original feelings. It is a long process for mothers to deal with the pain of their child’s death, but most do find joy in their lives again.

Factors Affecting the Grief Experience

Many factors affect the grief experience. It is helpful for anyone interviewing a bereaved mother or other family members to be aware of these factors and to be prepared for the wide range of grief expressions. Among the factors that shape the grief response are lost hopes and dreams for the child, family system factors, cultural influences, medical and legal system involvement, the age of the child, and the manner and cause of the child’s death.

Lost Hopes, Plans, and Dreams. A family’s hopes, plans, and dreams for their child affect how they grieve. Was this child the first girl or boy, or the first child or grandchild? Was the child named in honor of a parent, grandparent, or other relative? Has the family experienced a previous fetal or infant loss? What was the cause?

After the loss, another misfortune for some couples is the inability to have another child. Infertility may be due to any number of reasons, but the result is the same: another loss. Consequently, grief may be more intense if there is little hope of having more children.

Family Dynamics. The death of a child should also be thought of as a crisis of family development. It increases the family’s emotional burden and shatters the family’s ordinary life routines and coping mechanisms. The grieving family’s first priority is to restore stability in order to support family development (8).

A mother grieves as an individual but also within the context of the family. It is important to know the members of her family, their ages, sexes, and roles in the family. Is this a single- or teen-parent household? Are the husband or grandparents living in the home? Was this a first child? How many other children are in the



home? What are their ages? How do family members communicate with one another? Who makes the everyday and major decisions? The answers to these questions help the interviewer identify family strengths and sources of support. These strengths assist family members as they grieve their child's death and cope with other preexisting crises and problems.

Cultural Influences. Every culture has its own distinct way of easing the suffering of grief by offering the bereaved an explanation for the meaning of death and a prescription for how to proceed with life. The interviewer should consider the following questions about the family's culture. What are the religious, folk, or spiritual beliefs of family members? What does death mean to the mother? What customs, rites, and rituals surrounding death are important to this mother? What language is spoken? Additional information about cultural influences is provided in the section "Cultural Competence" later in this manual.

Health Care and Legal System Involvement. Grieving families encounter many health care providers at the time of their child's death or during the course of treatment. In sudden and unexpected deaths, the members of the family deal not only with health care providers but also with ambulance and emergency medical service personnel, police investigators, and medical examiners. Most providers respond in a sensitive and caring manner. However, any of these personnel may be (or be perceived to be) insensitive to the family's needs and concerns, adding to their grief and burden. In rare instances, the mother might feel that a provider contributed to the child's death through negligence or maltreatment. If these concerns are present, the mother is likely to be angry and resentful.

In some cases, social service personnel may investigate the care and safety of other children in the home. This process may increase feelings of guilt about the baby's death. In a few instances, social services will take the next step and remove children from the home during the investigation process. The family then also grieves the loss of these living children.

Age of the Child. The age of the child usually does not affect the severity of grief. A mother who loses a child to miscarriage or ectopic pregnancy may be as devastated as one whose older child has died. However, the family and community responses to the



“Each mother expresses grief in her own way. Initially, when told that a child has died or is going to die, she may be in shock. Her world has been turned upside down and her life is changed forever.”

death often are influenced by the age of the child. For example, there is a widespread misconception that the loss of a fetus is not as painful as the loss of a child and, therefore, little or no support is offered. In addition, friends and neighbors may not be aware of an early pregnancy loss and so do not offer support.

Manner and Cause of Death. There are many reasons a child may die during pregnancy or infancy. Some of these include failed fertility treatment, early miscarriage, therapeutic termination, ectopic pregnancy, fetal death, stillbirth, neonatal death, SIDS, birth defects, medical conditions, unintentional injury, and homicide. When the death of a child is sudden and unexpected, family members have no time to prepare and the intensity of their grief may be overwhelming.

The cause of a child’s death also may affect the grief response. Reactions often differ depending upon whether the death was natural or accidental. It is normal for families to assume some responsibility for a child’s death because they feel a duty to protect their children. When a child dies of natural causes, however, the family can be reassured that nothing could have prevented the death.

In contrast, families whose child dies from an accident such as choking or drowning are more likely to feel responsible for the death. In some cases, some friends or neighbors may also blame them for the death.

Expressions of Grief

When a parent dies, you have lost your past. When a child dies, you have lost your future. (9)

When talking to the mother or other family members in the home, the interviewer should be prepared to encounter a variety of emotional responses. The emotional responses described in this section are normal. The interviewer who is aware of the wide range of normal grief reactions is better able to distinguish between normal and abnormal responses and to refer to other sources of support as needed.

Each mother expresses grief in her own way. Initially, when told that a child has died or is going to die, she may be in shock. Her world has been turned upside down and her life is changed forev-



er. Later, feelings of sadness emerge. Anger, guilt, and fear may also be present.

A mother may not always be looking for answers to all of her questions about why the baby died. She may just need someone to sit with her and listen to her pain. For many, the opportunity to discuss the life and death of the child brings comfort.

Normal Responses. The following expressions of grief are normal responses to the death of a child.

Numbness and shock may be the first response to the death. Many mothers feel numb and are unable to express any emotion. In contrast, others may be hysterical or out of control, lashing out at other people or objects within reach.

Searching and yearning for the baby are frequently experienced. A mother often has a desire to remain close to the baby both physically and emotionally. She may hold or display pictures, clothing, or other objects related to the baby. She might even find herself preparing a bottle before she remembers that the baby has died. She may hear a baby crying and look for him or her. She may visit the gravesite often.

Sadness and depression are common. A mother may be unable to return to activities of daily living for an indefinite period of time. Feelings of hopelessness and withdrawal from friends and social activities are common. Low energy, general fatigue, and changes in sleeping and eating are also observed. Other symptoms of depression include indecision, lack of concentration, and forgetfulness.

Angry feelings are frequently observed. The anger may be directed at oneself for not having kept the child alive or toward the person who was caring for the child at the time of death. Sometimes the mother is angry with the dead child for “leaving me” or with her other children for demanding attention or acting out. A mother may direct anger at health professionals for having failed to save the child. Another common reaction is to be angry at God for taking the child away, for “punishing me.”

Helplessness and hopelessness are also feelings some experience. These feelings can be related to the perceived lack of control over life.



Guilt is often present. A mother may wonder if something she did or did not do contributed to the death of her child. She may wonder whether there is something wrong with her or whether she carries a defective gene.

Fear may be evident in several ways. A mother may often be fearful of “going crazy.” There is fear that something else will happen, that another loved one will die. Some may not allow their other children out of their sight for fear they will die, too. Others fear being alone, isolated, and abandoned.

Physical changes also are observed. A mother may experience loss of appetite, weight loss or gain, chest pain, abdominal and muscle pain, aching arms, or high blood pressure. After a still-birth delivery, mothers may describe feeling fetal movement, which can be very upsetting. Sleep disturbances are common. Physical intimacy is difficult for some couples and may lead to sexual dysfunction.

Psychological changes include an inability to concentrate or make decisions. A mother may also have auditory sensations of the baby crying or calling out to her. Sometimes she may also have visions of the baby.

Mothers’ and Fathers’ Grief. The death of an infant can create stress in the relationship between the parents. Some couples blame themselves or each other for the loss. They may feel that they have failed as parents. Their grief reactions also might vary, leading to a situation where one partner judges the other as not grieving as much. The interviewer can help by assisting the couple to be aware of the differences in the ways that individuals grieve and the importance of maintaining communication.

Foster Families. Foster families have unique grief issues when an infant dies in their care. Their grief experience may be just as intense as that of biological parents, but foster families have less personal or professional support. Family and friends often are not aware of their attachment to the baby or do not understand the depth of their feelings. In some jurisdictions, the foster care system breaks contact with the family as soon as there is no child in care.



There may be conflict between the foster family and the biological parents. Foster families may be expecting anger and hostility from the birth parents, but it is traumatic for them nonetheless. The biological parents may have objected to the placement of their child in foster care.

Biological parents may be plagued with the thought that their baby may have lived if he or she had remained in their care. In rare cases, they might believe that the foster family abused or neglected their child. The biological parents may ban the foster family from funeral services. The presence of the foster family at the funeral could further reinforce the parent's sense of inadequacy in front of family and friends. Referral for professional grief counseling may be appropriate to help both foster and biological parents deal with these complex issues.

Grandparent Grief. A grandparent may be a baby's primary caretaker. Many are happy to care for an infant again and enjoy this opportunity. Some grandparents view caring for a grandchild as a welcome opportunity to correct the mistakes they made with their child. Others approach this responsibility with reluctance. Evelyne Longchamp of the New York City SIDS Center reports that many grandparents are ambivalent about the role of parenting again. One grandmother said it felt like she was repeating a class she had failed.

When a child dies in the grandparents' care, their grief is twofold. They grieve both for their grandchild and for their own child. In some instances, the mother may be very angry and blame the grandparent for the infant's death. These grandparents have to deal with their child's accusations and resentment on top of their own feelings of loss. Thus, grandparents who are primary caregivers may have complex needs and require a level of support similar to that provided to mothers.

Children and Grief. Brothers and sisters also grieve in different ways according to their age, understanding of death, relationship with the dead child, ability to express feelings, and style of relating to and dealing with the world. Children often grieve deeply. They may experience sadness, confusion, and anger and often blame themselves for the death. Family members need to guide

“Children often grieve deeply. They may experience sadness, confusion, and anger and often blame themselves for the death.”



Table 1.
Normal Reactions of Surviving Siblings After Infant Death

REACTION	APPROACH
Fear of loss and separation from parents	Reassure children that parents are not leaving them. Tell them in advance about any impending separation (e.g., a trip to the store). Allow children to stay in close proximity to family members.
Guilt secondary to feelings of jealousy, anger, and dislike of the infant	Assure children that wishing their sibling dead did not cause the baby to die; let them know they could not have prevented the death.
Concern for their own lives	Let children know that infant death (e.g., a SIDS death or death due to prematurity) happens to young infants and will not happen to them. Try to avoid being overprotective, which reinforces their fear.
Fear about personal needs and asking “who will take care of me?”	The intensity of the family’s reactions can frighten children. Continuation of routine activities assures them that life will go on.
Disappointment and anger that the baby is gone and family expectations have now changed again	Talking to children and encouraging them to express their feelings reduces their anger.

Adapted from: McClain, ME and Shaefer, SJM. Supporting families after sudden infant death. *Pediatric Annals*. 1994 Vol 24(7): 373–378.

and support them. Professionals can assist the family in this process. Table 1 shows some common reactions of surviving children and approaches to dealing with these reactions. Table 2 lists some of the ways in which children react to death.

Adolescent Grief. Developmentally, adolescence is a time to become independent from one’s family. After a child’s death, an adolescent mother may be conflicted about whether to stay connected to the family for comfort or to try to handle the problem on her own to demonstrate autonomy. She may be particularly reluctant to share her feelings if the family was not supportive of the pregnancy. The challenge for the interviewer is to respect the adolescent’s role as mother and provide an opportunity for her to tell her story.

Some factors affecting the adolescent grief response include the age of the mother, how much the pregnancy was wanted, the mother’s relationship with the family, and the family’s response to the pregnancy and death. For many adolescents, this



is the first death of a loved one. They may not have had the life experiences to help them understand their grief.

Sometimes an adolescent mother will respond as she sees the adults in her environment respond. When a teenager is unsure how to respond, she may appear to be indifferent or to have no response. It is more likely that a teenaged mother deeply grieves the baby's death but shares her feelings with peers and the baby's father, not with adults. Jodi Shaefer, former director of the Center for Infant and Child Loss, describes one teenager's response to loss:

A teen's baby boy died of SIDS. After the baby was born, the teen took care of him while she continued in high school. The baby slept in her room. After the baby died, the teen's father called the SIDS Center to express concern that the teen wasn't grieving. When the counselor contacted the teen, she readily talked about her sadness and emptiness since the baby's death. She also talked regularly with the baby's father about their shared loss. He was supportive. The teen simply did not want to discuss her feelings with her family. She preferred to talk to friends and the baby's father.

Health Care Provider Responses at Time of Death

The family is deeply affected by the response of health care providers at the time of a child's death. Many health care providers are very supportive. The willingness of health care providers to listen to painful expressions of loss is an important element in facilitating the grief process. Although family members might not remember exactly what health care providers said at the time of the death, they would certainly recall whether they displayed a caring attitude and offered comfort.

Occasionally, a service system or provider does not meet a family's needs. For example, some mothers have told interviewers that they feel their babies would have gotten better care or more intensive treatment if they had regular insurance, not Medicaid. In rare cases, a mother may express anger at a

“When a teenager is unsure how to respond, she may appear to be indifferent or to have no response. It is more likely that a teenaged mother deeply grieves the baby's death but shares her feelings with peers and the baby's father, not with adults.”



Table 2.
How Children React to Death

AGE	CHILD'S REACTIONS	HOW TO HELP
Birth to 3 Years	<ul style="list-style-type: none"> • Affected the most by the mood of their caretaker. • Little understanding of death. • You may see changes in sleeping patterns, eating habits and mood. • Older infants and toddlers might demand more attention. 	<ul style="list-style-type: none"> • Maintain routines and familiar places. • Provide abundant love, attention and reassurance. • Provide a caring substitute if the parent is too distraught to respond.
3 to 6 Years	<ul style="list-style-type: none"> • Does not understand that death is permanent. • Fears the dead person is cold or hungry. • May have bad dreams, revert to earlier behaviors, and/or physical symptoms. • Repeat questions about death. • May play-act the events surrounding the death. • May fear that others and/or self will die. • May be afraid to go to sleep. 	<ul style="list-style-type: none"> • Maintain routine and provide abundant affection and attention. • Shorten time away from the child. • Look into the child's eyes and gently hold them when speaking of death. • Use concrete terms such as <i>dead</i>, <i>Tommy doesn't eat, sleep, go to the bathroom or grow</i>. • Avoid words such as <i>sleeping, resting, lost, passed away, taking a long trip, and God took him</i>. • Repeat answers as often as the child asks. • Allow expressions of feelings, by re-enacting the events surrounding the death, drawing, reading and telling stories about the death. • Give assurances that most people don't die until they are much older.
6 to 9 Years	<ul style="list-style-type: none"> • Views death as a mysterious thing that comes and takes people away or can be caught like a cold. • Some may still not think of it as permanent. • May feel responsible because of actions, words said or wishful thinking, i.e. wishing sibling dead. • Child could be distressed, sad, or show no signs. • Fear of loss or abandonment by other members of the family. • May be obsessed with the causes of death and what happens to the body after death. 	<ul style="list-style-type: none"> • Provide the child with time to talk to you about their ideas and feelings, answer questions honestly and correct confusing ideas. • Maintain routine. • Reassure that the death was not their fault. • Contact the school. • Allow them to participate in pre and post funeral activities if they desire. • Provide a journal for the child to write or draw thoughts and feelings. • Let them know where you are going and when you will be back, and, if at all possible, how they can reach you.



health care provider for a perceived lack of support or inadequate care of the baby. The interviewer can listen to these emotions, validate the feelings, and remain nonjudgmental. The goal is to obtain the mother’s perspective on her care and validate her grief response. If appropriate, the interviewer can reassure the mother that everything was done for the baby.

These angry feelings can complicate and interfere with the grief process. Generally, the mother needs to discuss these responses with the provider. The interviewer can simply convey this message.

AGE	CHILD’S REACTIONS	HOW TO HELP
9 to 12 Years	<ul style="list-style-type: none"> ▶ Understands that death is permanent. ▶ May view the death as punishment for bad deeds. ▶ May seem to be unaffected by death. ▶ Could show anger directed at others and self. ▶ May show feelings of guilt, grief and responsibility. ▶ Physical symptoms. 	<ul style="list-style-type: none"> ▶ Give assurance that the baby didn’t die because he/she was bad. ▶ Encourage participation in pre and post funeral activities. ▶ Encourage the expression of ideas and feelings. ▶ Contact school. ▶ Be honest about what you are feeling—if it is age appropriate. ▶ Provide affection and support.
Teens	<ul style="list-style-type: none"> ▶ Adult understanding of death. ▶ May assume responsibilities for adult concerns, family well being, money, etc. ▶ May feel confused, sad, responsible, angry, lonely, afraid, guilty. ▶ Physical symptoms. 	<ul style="list-style-type: none"> ▶ Talk without criticizing or judging. ▶ Be honest about what you are feeling and experiencing. ▶ Discourage the assumption of too much responsibility. ▶ Be willing to talk on the teen’s time frame. ▶ Allow teens time to be alone and to grieve in their own way. ▶ Encourage participation in pre and post funeral activities.

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CHAPTER 4

FIMR interviewers must be skilled in interview and active listening techniques and must be culturally competent. Training is therefore essential for all FIMR interviewers, both before the initial interview and on an ongoing basis. FIMR interviewers also need to be introspective and self-aware. Interviewers need to assess their own counseling skills, abilities, and attitudes and recognize any areas that might need improvement (Table 3).

Supportive Listening

“As to what to say to a grieving parent, the simpler the better. We can recall the horrible things uttered by people who meant to be kind. They relied on old platitudes, which at times of distress are even more meaningless than usual. To hear that we could have more children, that Brianne was better off dead, or that God only gives you what you can handle, did little to salvage our broken hearts. A better tack is to become a good listener, and let the grieving parents set the tone. Try not to be intimidated by tears. They are all important parts of both the grieving and healing processes. And don't be insulted if the parents don't want to talk. A hug and a goodbye is sometimes most appropriate.”(10)

It is a challenge to sit and listen to the pain that bereaved mothers express. Mothers may have had to deal with inexperienced family members or friends who did not know how to help the bereaved family. One bereaved mother responded to well-meaning friends and relatives by asking, “Could you please just listen?” She did not want to be told that it could have been worse or that God wanted another angel. Nor did she want to hear stories of someone else's death. She did not want to be distracted. She wanted someone to listen.

Practice and attention to the fine points of the interviewing process improve supportive, active listening skills. Four major components of those skills are discussed in the following paragraphs.





Table 3.
**How To Assess Your
Counseling Skills, Abilities,
and Attitudes**

Listening Skills

Do you: Hear the mother’s attitudes and feelings without pre-evaluating or prejudging them?
Listen and try to understand the thinking and concerns of the mother?
Ask open-ended questions that promote disclosure from the mother?

Skills of Empathy

Do you: See the issue(s) from the mother’s point of view?
Feel genuine concern for the mother and family?

Effective Communication

Do you: Communicate clearly and effectively with the mother?
Maintain eye contact and reflect content and feelings presented by mother ?

Realistic Analysis

Do you: Have a realistic and accurate picture of the mother’s current situation?
Have information about all family members? (Consider extended family members.)

Attention to Self

Do you: Identify your own emotions as you work with the mother?
Know your own attitudes and feelings about death?
Identify and manage the impact on yourself?
Seek out and use appropriate support and supervision?

(Adapted with permission from: The California Department of Health Services, Maternal and Child Health Branch. The California SIDS Program. A Practical Guide to the SIDS Home Visit. Sacramento CA. 2001California SIDS Program, A practical guide to the SIDS Home Visit pp 2–3, 2–4)

1. Paying Attention to the Mother (“Attending”):

- Look at the mother. If other family members are present, keep them in view to observe their reactions, but generally maintain eye contact with the mother. This shows that the interviewer is comfortable and calm. Avoid “rabbit eyes”—darting from object to object in the room. This suggests the interviewer is nervous or uncomfortable.
- Reassure the mother that she did everything that she could, that the medical care for her baby was the best, or whatever is known to be true and positive about the case.
- Show interest in what the mother is saying. Encourage her to continue by the unobtrusive use of “yes,” “I see,” “um hum.” Use positive body cues at appropriate points—nods, smiles, taking notes, raised eyebrows, etc.
- Most of the time, lean slightly toward the mother. Keep an open, relaxed posture. Keep physical movement to a minimum. Avoid distracting mannerisms, such as twisting hair or playing with a ring. These undermine credibility. Many people are unaware of their mannerisms. When role-playing the interview, ask a partner to point out any such behaviors.
- Engage the mother by looking for opportunities to subtly mirror her cues. Do not mimic, but do look for ways to be congruent. For example, if she speaks slowly, match her pace.
- When appropriate, draw the mother out. Say something like, “I’d like to hear a little more about [subject].”
- Try to listen for what is *not* being said—what’s missing that might be expected in these circumstances?
- Observe how things are said—the emotions and attitudes behind the words may be more important than what is actually said. Look beyond the mere words the mother uses—remember that much information is displayed in voice intonation and body language.
- Say little! It is not possible to listen and talk at the same time.
- Show interest by asking questions and giving feedback, reframing, and summarizing. However, particularly in the early stages of the interview, be careful not to interrupt the mother’s flow.



2. Asking Questions

Questions serve three basic purposes:

1. To show interest and an active listening style (especially in the early, trust-building stage)
2. To gather and organize information
3. To express in question form what otherwise might be an academic statement—for example, to test reality

The FIMR interview contains both open-ended and closed-ended questions. Close-ended questions can be answered “yes” or “no,” or with a specific answer like “two” or “January.” They encourage the mother to give the answer and stop talking. Open-ended questions cannot be answered so simply and encourage the mother to talk and explain in complete sentences. Each section of the interview ends with the open-ended question “Is there anything else you would like to tell me?” These open-ended questions are important because they invite the mother to open up and tell her story. Examples of open-ended questions:

- “Tell me more about [subject].”
- “What happened next?”
- “How did you feel when that happened?”
- “What would you like to see as an outcome?”

3. Providing Feedback, Reframing, and Summarizing

- When the mother pauses, there’s an opportunity to confirm active listening and understanding by providing feedback on what the mother said. Giving feedback is also a way to check the accuracy of what has been heard and observed and to validate for the mother what she is feeling.
- To provide feedback, repeat or paraphrase what the mother has said (or displayed as unspoken feelings). Examples:
 - “So, when that incident happened, you felt...”
 - “It sounds like an important issue for you is how to deal with...”
 - “What I think I’m hearing is that you really need to...”
 - “I can see that you have strong feelings about that.”



Pause expectantly to let the mother react. Common signs that this has been done right: the mother will nod vigorously and/or respond, “yes, and....”

- Sometimes, repeating the last couple of words that a mother has spoken encourages her to go on, but generally do not repeat verbatim what the mother said—this may sound like you are mimicking her. Paraphrase instead. However, do be conscious of particular words that seem important to the mother and use them, if appropriate, in paraphrasing.
- Reframing is a special way of giving feedback and is one of the interviewer’s most important tools. Reframing is a way of restating what the mother has said to capture the essence, remove negative overtones, and move the process forward. Reframing is also a way to translate a positional statement into a statement of interests or needs. Example: A separated mother says angrily, “He was so irresponsible that I never could depend on him to pick our baby up on schedule.” Simple feedback might be, “So it really bothered you if he wasn’t on time to pick up Johnny.” A reframed response might be, “So a regular schedule is important for you.” Either response may be appropriate.
- In general, use neutral verbal language and neutral body language. Don’t let the mother feel that she is “failing” the interview based on negative cues or verbal messages. Example: If the mother says she did not go for prenatal care and still doesn’t think it is important, don’t frown, pull back, or begin a lecture on the importance of prenatal care. Try saying, “I can see that you have strong feelings about that. Tell me more about why you feel that way.” When the mother gives her reasons why she does not value prenatal care, the interviewer may be able to address her concern. “But since I hear you saying you will try to get pregnant again, there are new clinic services available that do have scheduled appointments and evening hours just as you have wanted all along.”
- Use neutral language to diffuse negative feelings. The father might say the mother was “hysterical.” In giving feedback, the interviewer might say the mother was “crying.” The mother might say that she thinks someone “lied” to her. The interviewer might say the person “disagreed” or “saw the situation differently.”



4. Managing the Flow of Communication

- Let the mother finish discussion of one topic before going to another subject. You may want to go to something else, but give the mother time to finish.
- Don't be too quick to try to move on when the mother repeats things. Remember, repetition may indicate: (a) that the subject is very important to the mother and (b) that the mother needs to feel that she has really been heard on the subject. This is a cue that the interviewer might need to give feedback on what the mother is saying.
- If repetition does go on too long, try saying something like, "Well it's clear to me that [subject] is very important to you. Is there anything else that's also important for us to understand?"
- Be comfortable with silence. Usually, the mother will speak up soon enough. Use silent cues—pauses, turning to her expectantly.

Adapted from: The Veterans Administration. Active listening for mediators. [Online, 2002 www.va.gov/adr/active], Schimdt, L. Parent Bereavement Outreach. Santa Monica, CA and Bell, AH. More than words can say. Nursing Library May 2000 {Online 2002 www.findarticles.com}

Table 4 lists examples of statements made by family members during FIMR home interviews and suggestions for responses. These statements provide an idea of what to expect when speaking with family members. Although this manual also offers some advice about how to respond, the interviewer needs to keep in mind that there are no easy answers and no standard approaches that are universally helpful. There are no magic formulas that will make the pain go away. Families are more likely to reach a healthy, positive resolution of their grief if they receive continuing support and understanding.

The interviewer should review these comments and the suggested responses that accompany them and should discuss them in training sessions. Interviewer should also role-play the interview with several colleagues to practice responding to these concerns before the home visit takes place. Table 5 lists "do's and don'ts" in working with bereaved families.



Table 4. Family Questions and Concerns

Practical Concerns

- Should I have a memorial service/funeral for my baby?
- I don't have the money to pay for my baby's funeral.
- When will my baby be released from the medical examiner's office?
- I wish he'd been christened.
- What do I say when people ask how many children I have?
- How will I survive the holidays, or my baby's death, anniversary, and birthday?
- What is an autopsy? Should I get the report?
- How can I get the death certificate?
- I don't have the money to pay for the death certificate/autopsy report.
- What should I do with clothes, crib, carriage, and toys?
- What should I do with the pictures?
- The police took my baby's bed and toys. Can I get them back?
- I have miscarried so many times. Will I ever have a baby?

The interviewer should know about and be prepared to link parents to culturally appropriate pastoral care or offer other information, such as available funeral and burial options, as appropriate. Although this varies from state to state, the interviewer should also know how to assist the mother in obtaining birth and death certificates and the autopsy report, if one was performed. Some questions that the mother asks might be reflected back to her for clarification. For example, when a mother asks, "What should I do with my baby's pictures?" the interviewer might say, "What would you like to do with the baby's pictures?" The mother might be getting conflicting advice from family and friends. The interviewer can support the mother's decision.

Natural Grief Reactions/Feelings

- I cry all the time.
- I have no energy.
- I can't sleep/eat.
- I have really bad dreams.
- I can't make decisions/care for the house.
- I keep forgetting things.
- I'm so overprotective of the other children.
- I can't go out/I can't stay in.
- I don't want to talk to anyone/my partner/my other children/my family.

- I hear the baby crying.
- My arms ache to hold my baby.
- I can still feel my baby moving inside me.
- 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.

The interviewer can reinforce that such experiences are common among many grieving parents. Other parents report that they feel they are "going crazy." The interviewer can again reassure the bereaved that other parents spoke and felt the same way.

Loss

- I have to talk to someone about my baby.
- Help me. I'm so alone.
- 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's face.

The interviewer should listen and provide comfort. Parent-to-parent peer support and/or ongoing bereavement counseling can be very helpful. The interviewer should be able to make culturally appropriate referrals.

Guilt

- If only I had...awakened earlier/found him in time/nursed him/not smoked/taken medicine/not worked.
- What could I have done differently?
- It must be my fault.
- Why didn't I go to the hospital right away?
- What did I miss?
- Was I a good mother?
- Am I being punished?
- Why me, God?
- What kind of woman am I if I can't carry a baby to term?
- My in-laws are telling everyone that it was my fault.



Some mothers search their memories over and over again for the slightest evidence that they failed to do the right thing. These mothers need to be assured that almost all bereaved mothers think this way and that these feelings are normal. For other mothers who actually may have been negligent in some manner, the challenge for the interviewer is to validate the mother's grief response without adding to her feelings of guilt. Listening without judgment will be greatly appreciated by the mother. If the death was a preventable accident, the interviewer might simply state that the accident is a tragedy and was not done on purpose. However, some mothers may need ongoing counseling, and the interviewer may offer to make a referral.

Anger

- ▶ Why doesn't anyone listen/care?
- ▶ How could God let this happen?
- ▶ My partner doesn't care about how I feel.
- ▶ People are bugging me.
- ▶ 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 did the baby leave me?

The interviewer should remember that some mothers may not always be looking for answers to all their questions. They just need someone to sit with them and listen to their anger and pain. The interviewer should not take the anger personally. Grief drives the mother's anger. If anger is directed at health care professionals, the interviewer may acknowledge how difficult that situation must have been and say "what do you wish they would have said or done?" The interviewer may say that some providers may have a hard time dealing with the death of a baby and that they may need more education and support. The goal is to explain the behavior, not to defend the provider's actions. If anger is directed at God, the interviewer should listen and be able to refer to the appropriate spiritual counselor, if the mother desires a referral.

Adapted from the California Department of Health Services. Maternal and Child Health Branch, California SIDS Program. A Practical Guide to the SIDS Home Visit. Sacramento CA. 2001; American College of Obstetricians and Gynecologists Patient Education Bulletin AP078 Grieving: a way to heal. 1996 Simpson KR and Chrelker PA. AWHONN Perinatal Nursing. Philadelphia, PA: Lippincott 1996, p 276 and de-identified reports of New York State FIMR home interviewers 1990–1994.

Cultural Competence

"Bereavement is a universal human experience. However, each human being deals with loss and grief within a very individual context, shaped by ethnic, cultural and religious factors and expectations." (11)

Cultural heritage strongly shapes expressions of grief and loss. A cultural group can be defined as people who share a common origin, language, customs, styles of living, and sense of identity. Even within a given cultural group, however, the extent to which the grief reaction is influenced by cultural beliefs and practices varies across individuals and families. Key factors affecting this reaction include immigration status, age of the mourner, family traditions, gender, one's faith foundation, geographic region, education and income, prior experiences with death and loss, and the historical background of the cultural group. (For a more in-depth information on cultural issues, read the NFIMR Bulletin "When an Infant Dies: Cross-Cultural Expressions of Grief and Loss").

The home interviewer's feelings and responses are also influenced by her or his own cultural background, which may differ from that of the mother. It is important to understand cultural differences in expressions of grief and to be nonjudgmental



Table 5.

Do's and Don'ts in Working with Bereaved Families

—**Don't try to find magic words that will take away the pain.** There aren't any. A hug, a touch, and a simple "I'm so sorry" offer real comfort and support.

—**Don't be afraid to cry.** Your tears are a tribute to both the child and the parents. Yes, the parents may cry with you, but their tears can be a healthy release.

—**Avoid saying, "I know how you feel."** It is very difficult to comprehend the depth of the loss when a child dies, and to say that you do may seem presumptuous to the parents.

—**Avoid saying "It was God's will" and using other clichés that attempt to minimize or explain the death.** Don't try to find something positive in the child's death, such as, "At least you have other children." There are no words that make it all right that a child has died.

—**Listen! Let them express the anger, the questions, the pain, the disbelief, and the guilt they may be experiencing.** Understand that parents often have a need to talk about their child and the circumstances of the death over and over again. It may be helpful to encourage them to talk by asking a gentle question such as, "Can you tell me about it?"

—**Avoid judgments of any kind.** "You should..." or "You shouldn't..." is not appropriate or helpful. Decisions and behaviors related to displaying or removing photographs, reliving the death, idealizing the child, or expressing anger, depression, or guilt may appear extreme in many cases. These behavior patterns are normal, particularly in the first years following the child's death.

—**Be aware that, for parents with religious convictions, their child's death may raise serious questions about God's role in this event.** Do not presume to offer answers. If the parents raise the issue, it would be better to listen and allow them to explore their own feelings. They will need to arrive at an individual philosophy about this.

—**Give special attention to surviving children.** They are hurt, confused, and often ignored. Don't assume they are not hurting because they do not express their feelings. Many times siblings suppress their grief to avoid adding to their parents' pain. Talk to them and acknowledge their loss.

—**Mention the name of the child who has died.** Don't fear that talking about the child will cause the parents additional pain. The opposite is usually true. Using the child's name lets parents know that they are not alone in remembering their child.

—**Be patient.** Understand that each grieving family responds differently to their pain. Some verbalize, others may seem unable or unwilling to talk, some withdraw, and others strike out angrily.

—**Gently encourage a return to outside activities.** Suggest a long walk or lunch or movie with family or friends as relief from the isolation of grief.

—**There is no standard timetable for recovery.** Grief usually lasts far longer than anyone expects. Encourage bereaved families to be patient with themselves. They often hear, "Get on with your life; it's time you got over this!" Those demands are unfair and unrealistic. When parents express concern about being tired, depressed, angry, tearful, unable to concentrate, or unwilling to get back into life's routines, reassure them that grief work takes time and that they may be expecting too much of themselves too soon.

—**Be sensitive to the changes a bereaved family experiences.** Other family members will adopt new behaviors and roles as they learn to live without the child. This is a painful and lengthy process. Prepare the family for this experience.

Adapted from: How Can I Help © The Compassionate Friends, Inc.



about the family's behavior. For example, emotional displays of grief are encouraged in some cultures but less acceptable in others. The interviewer should be careful not to judge the family's reaction by personal standards. Reactions to death and the grief response are unique and individual.

Although an interviewer may not have in-depth knowledge of every culture, she can be helpful if she approaches mothers with a supportive, nonjudgmental attitude. Mothers are usually willing to discuss cultural traditions that help them cope with the loss.

Some mothers and families have experienced racism and other forms of discrimination from providers in the health care system. These experiences can destroy the mother's trust and the expectation that providers will act on the mother's behalf. As a result, mothers may refuse to be interviewed. Interviewers may have to increase their efforts to identify and overcome these barriers.

Although cultural traditions play a role in the way a person responds to loss, these beliefs are not static. Especially in today's world, communication technologies, global news broadcasts, and extensive migration are creating an environment in which traditional customs are constantly changing.

Meeting the diverse needs of bereaved mothers is a challenge to home interviewers. At the same time, the experience affords a unique opportunity for interviewers to assist and support mothers and families through one of life's most difficult times, the death of a child. To do this effectively, interviewers must appreciate cultural beliefs and practices that differ from their own. There is no one reference that answers all questions for every culture. The best approach is to be nonjudgmental and respectful. To build a therapeutic, culturally competent relationship, the interviewer can simply state,

"I am so sorry for your loss. How can I help you?"

FIMR Interviewer Training

Training in interviewing and active listening techniques, cultural competency, and bereavement counseling is essential for all FIMR interviewers both before the initial interview and on an ongoing basis. Before conducting a FIMR interview, the interviewer should ensure that she knows how to:

- Track, contact and engage mothers
- Review and explain the consent form



- Prepare to conduct the interview
- Provide culturally sensitive bereavement support during the interview
- Listen and record, not interpret
- Conduct a standardized interview with open-ended and limited-response questions
- Maintain confidentiality
- Comply with public health and safety codes related to home visiting and pertinent reporting requirements
- Handle difficult encounters and recognize personal safety issues and when to conclude or omit an encounter
- Screen for suicide risk
- Avoid implications of mismanagement and liability
- Refer to needed services when requested

At a minimum, interviewers must have sufficient training to ensure that they do no harm. If the interviewer has only basic skills, she should find a mentor with more advanced training.

CHAPTER 5

Summarizing FIMR Interview

Various methods can be used for summarizing the interview for case presentation. To be completely objective and hear the mother's whole experience, most case review teams request that all of the information given by the mother, not just portions selected at the discretion of the abstractor or interviewer, be presented. In some projects, the interviewer and medical record abstractor are different people and may choose to write up a summary of their information separately. Others pool their information into a single narrative summary, either combining the information or dividing it into different sections.

NFIMR believes that it is important to compare and contrast the information that the mother provides with that contained in the medical records. This format supplies the most comprehensive information to the FIMR review team and facilitates the identification of gaps and duplication of services and resources. The method developed jointly by the Bay, Franklin, Gulf Healthy Start Coalition, Inc, Florida FIMR and Healthy Mothers/Healthy Babies, Broward County Florida FIMR is recommended (Figures 6 and 7). This format has a two-column, side-by-side format. Categorized sections correspond to the FIMR case summary deliberation sheet. Information abstracted from the medical record is presented in one column, and maternal interview information is in the other. Both the fetal and infant case summary formats are incorporated in text, and a diskette with these summaries is included with the Home Guide.

Letters and numbers in the maternal interview column correspond to the Home Interview Form and indicate where the information is inserted. For example, "A1" would be from maternal interview section A, question 1. Although the categories are in boldface, it is more visually appealing to have answers in plain print. Because of space constraints, the interviewer may not be able to answer in complete sentences. Supplemental information that helps tell the mother's story can be summarized and inserted in the write-in section.





Figure 6.
Abstracted Interview Fetal Case Summary

CASE PRESENTATION #
(INFANTRB.DOC)

CASE PRESENTATION #

Vital Statistics Fetal Death Certificate Information:

Sex: _____

Cause of Death: _____

Weight: _____

Weeks Gestation: _____

Mother: _____

Previous Pregnancies: _____

Father: _____

Prenatal Care: _____

Weight Gain: _____

Substance Use: _____

Delivery: _____

Case summary synopsis: (information from medical record)

The mother was (age, gravida, para, race/ethnicity, marital status, education, occupation). She entered prenatal care at ____ (weeks) at a _____ (place) with care by _____ (provider) with _____ visits. Medical history was significant for _____. Prenatal history was significant for _____. Prenatal referrals included _____. She delivered at _____ (place) at ____ weeks gestation) by _____ (delivery method). Events up to delivery included _____. Birth weight was _____. An autopsy was/was not done. Findings included _____. Bereavement support was/was not done.

(continued on page 59)

NFIMR abstracting forms are abbreviated as follows:

- PRE = Prenatal
- L&D = Labor and Delivery
- NEW = Newborn Assessment
- NICU = Newborn Intensive Care
- AMB = Ambulatory Care
- Aut = Autopsy Form
- Ped E/D = Pediatric Emergency Department and/or Hospitalization
- Baby Health at Home
(Supplement to Maternal Interview)

[From the format originally developed by Ursula Hearn and Kay Fillingim (Bay, Franklin, Gulf Healthy Start Coalition, Inc. Florida FIMR) and adapted by Dani Noell, Feona Mathis, and Georgia Modreck (Healthy Mothers/Healthy Babies, Broward County, Florida FIMR)]



(continued from page 58)

MEDICAL RECORD	MATERNAL INTERVIEW
<p>I. MEDICAL: MOTHER</p> <p><i>Prenatal Medical record:</i></p> <hr/> <p>Mother 7, 3, 4, 5, 6, gravida 14, para 14</p> <hr/> <p>Previous Pregnancies: 14 A, B, etc.</p> <hr/> <p>LMP: 13</p> <hr/> <p>EDC: 13 A by dates: 13 B by sonogram</p> <hr/> <p>HIV: 17</p> <hr/> <p>Prenatal labs: (Include blood type) 18.</p> <p><i>Results unremarkable except for:</i></p> <hr/> <p>Treatment was _____. Repeat at ____ weeks noted.</p> <hr/> <p>Pre-existing medical problems: 25</p> <hr/> <p>Medications: 24</p> <hr/> <p>Problems developed: 26</p> <hr/> <p>Nutrition: 29</p> <hr/> <p>Pre-pregnancy Weight: 27</p> <hr/> <p>Height: 28 B</p> <hr/> <p>Identified nutritional factors: 30</p> <hr/> <p>Gained: 28 by 28 weeks.</p> <hr/> <p>Body Mass Index:</p> <hr/> <p>Nutritional referrals: 31</p> <hr/> <p>Other testing/Procedures: (include weeks done and any referrals) 38</p> <hr/> <p>Hospitalizations: 42</p> <p><i>Labor and Delivery Medical Record:</i></p> <hr/> <p>Hospital Level: 1</p> <hr/> <p>Time: 2 Gestational Weeks: (write in)</p> <hr/> <p>Reason for Admission: (write in, include how long with symptoms of labor, what complaints and how arrived)</p> <hr/>	<p>I. MEDICAL: MOTHER</p> <p><i>She was E 1 and E 2 years old, was born E3, and is E4. She completed E6 and E7.</i></p> <p><i>Her baby was D1 and D1a&b. Prior to this pregnancy she was pregnant D 3, with D 4. D5.</i></p> <p><i>She was A1 weeks when she thought she might be pregnant. She was A2 when she was sure she was pregnant. She was A 20 with her care (Note: expand on issues if not satisfied). During her pregnancy she A 27.</i></p> <p><i>She took A34 special precautions to prevent preterm labor. (A35) She describes her health during her pregnancy as A 36.</i></p> <p><i>She was B 1 on a special diet. Her prepregnancy weight was B2, and she gained a total of B4 and she is B5 tall. She B8, She B3.</i></p> <p><i>Labor and Delivery: (Maternal Interview)</i></p> <hr/> <p><i>She was C1. and C2. She delivered in C3 on C7. Her due date was A3.</i></p> <p><i>She describes her delivery as C4. She spent C 5 nights in the hospital. C 8 - 9 - 10 - 11.</i></p> <p style="text-align: right;">(continued on page 60)</p>



(continued from page 59)

MEDICAL RECORD	MATERNAL INTERVIEW
<p>Admission History: write in evaluation at admission, stage of labor, condition, include BP if has a history of hypertension, note any abnormalities.</p> <hr/> <p>Membranes: 3 - 4 - 5</p> <hr/> <p>Monitoring: 10 A-B Include information of initial fetal heart rate and also rate prior to delivery.</p> <hr/> <p>Problems in labor and delivery: 11</p> <hr/> <p>Referrals: 18 - 20</p> <hr/> <p>Medications: 17</p> <hr/> <p>Anesthesia: 17</p> <hr/> <p>Delivery: 8 - 9 - 12 16 - 19 - 25A</p> <hr/> <p>Resuscitation: 13,14,15,15B,C</p> <hr/> <p>Discharged: 23 - 24 - 25B - 30 - 31 - 32 36</p> <hr/> <p>Placental exam: Write description or include abstracted findings.</p> <hr/>	<p><i>She says what happened is: Maternal Interview 1 page ii:</i></p>
<p>2. MEDICAL: FETAL</p> <hr/> <p>Autopsy: L&D 36 38 include if offered, by whom and if done or refused</p> <hr/> <p>Autopsy:</p> <hr/> <p>Evidence of Injury: (Aut 1) Cause of death: (Aut 2) Culture and Toxicology: write in</p> <hr/>	<p>2. MEDICAL FETAL</p> <p><i>The baby's death was explained: (2 on page ii Maternal Interview)</i></p>
<p>3. PAYMENT FOR SERVICES: MEDICAL</p> <hr/> <p>Payer source PRE 15, L&D 21</p> <hr/>	<p>3. PAYMENT FOR CARE</p> <hr/> <p><i>PRENATAL: Paid by A 10 and A16.</i></p> <hr/> <p><i>L&D: Paid by C 6.</i></p> <hr/> <p><i>Baby Home: 19, 20</i></p> <hr/>



MEDICAL RECORD	MATERNAL INTERVIEW
<p>4. PROBLEMS WITH PRENATAL CARE</p> <p>Prenatal care: PRE: First visit 2, 8, 13C, at 9, 10, 11 with ___ health care givers.</p> <hr/> <p>Prenatal Appointments: 39 - 40 - 41</p> <hr/> <p>L&D 22</p>	<p>4. PROBLEMS WITH PRENATAL CARE</p> <p><i>She A5 received prenatal care as early as she wanted by A4. (If not why, If yes delete.) It A7 was (not) difficult obtaining prenatal care. Her first prenatal visit was at A8 weeks at a A9. She A13 and A14 during the pregnancy. A6</i></p> <p><i>She A 15 during her prenatal care and A 19.</i></p>
<p>5. PROBLEMS WITH PEDIATRIC CARE: N/A</p>	
<p>6. SUBSTANCE USE</p> <p>Substance abuse: Pre 16</p> <hr/> <p>L&D 29</p>	<p>6. SUBSTANCE USE</p> <p><i>She B 15 - B 20 and she B 21 and 22 and she took B 23 - B 24. She A 22 if she was smoking and was A 23 told how it would affect her baby. She A 24 if she was drinking and A 25 how it would affect her baby.</i></p>
<p>7. PRENATAL RISK ASSESSMENT</p> <p>Healthy Start: Prenatal risk score: PRE 33, 34, 36, 37</p> <hr/> <p>Healthy Start: get information from Healthy Start Care Coordination. Include screening and services.</p>	
<p>8. INFANT RISK ASSESSMENT: N/A</p>	
<p>9. SOCIAL SUPPORT</p> <p>Psychosocial Assessment/ Social Issues: PRE 19, 20, 21, 22, 23;</p> <hr/> <p>L&D Psychosocial: 27 - 28 - 29 -</p>	<p>9. SOCIAL SUPPORT</p> <p><i>If a problem had come up in the 12 months before the baby was born H4 would have helped. The baby's father completed F 1 and F2 of education and is F3 and F4. She describes her relationship with the baby's father as F8 and she was F9 satisfied with his contributions financially. During the pregnancy the baby's father F10. She describes her relationship with the father now as F11.</i></p> <p style="text-align: right;"><i>(continued on page 62)</i></p>



(continued from page 61)

MEDICAL RECORD	MATERNAL INTERVIEW
<p>10. HOMELESS/TRANSIENT</p> <p>Pre 21 _____</p> <p>L&D 29 _____</p>	<p>10. HOMELESS/ TRANSIENT</p> <p><i>She felt G1 satisfied with her overall living situation. She G5 a G6 and paid G7 each month. She G9. She G8 in the past year. There was G10 afford a place to stay or when she couldn't afford the rent or mortgage and G11 from her home and G12.</i></p>
<p>11. POVERTY</p> <p>Pre 21 _____</p> <p>L&D 29 _____</p> <p>Include Additional Economic Services: Use if information regarding WIC, Medicaid, AFDC, etc. is available.</p>	<p>11. POVERTY</p> <p><i>During her pregnancy she felt she B9. She B 10 cut down on the amount of food she bought. There was B11. Sources of family income were G2 and her estimated yearly income was G4. Before the baby died, she G 13 worry about not having enough money from one month to the next.</i></p>
<p>12. MENTAL HEALTH/STRESS</p> <p>Pre 21 _____</p> <p>L&D 29 _____</p>	<p>12. MENTAL HEALTH/ STRESS</p> <p><i>During the 12 months before delivering her baby H 1-2-3. During the pregnancy the father experienced F 10.</i></p> <p><i>In the last month she has H 5 felt good about her ability to handle her personal problems and that difficulties H 6 were piling up so high that she could not overcome them. She has H7 felt depressed, down, or blue. Since her baby died she and her partner have H8 received counseling or joined a support group for parents who have lost a baby.</i></p>
<p>13. FAMILY VIOLENCE/NEGLECT</p> <p>Pre 21, L&D 29 _____</p>	<p>13. FAMILY VIOLENCE/ NEGLECT</p> <p><i>H 1, 2,3</i></p>
<p>14. CULTURE</p> <p>Write in _____</p>	<p>14. CULTURE</p> <p><i>E5, F5</i></p>
<p>15. TRANSPORTATION</p> <p>Write in _____</p>	<p>15. TRANSPORTATION</p> <p><i>She traveled by A11 to get there and it took A12. (Also A17, A18 if used). E 10, 11.</i></p>



MEDICAL RECORD	MATERNAL INTERVIEW
<p>16. PROVISION/ DESIGN OF SERVICES</p> <p>Documented education: Pre 35, Education not discussed: Pre 35</p> <hr/> <p>Education: L&D 26</p> <hr/> <p>Bereavement: L&D 34 35 37</p> <hr/> <p>Referrals: Pre 32, L&D 33,</p>	<p>16. PROVISION/ DESIGN OF SERVICES</p> <p><i>Education discussed with her during her prenatal care included A21. She was asked A26 and she attended A27. Nutrition B6 discussed with her. She B7.</i></p> <p><i>She B12 WIC. Advice given at WIC included B13. and it B14 to get WIC vouchers.</i></p>
<p>17. ENVIRONMENT/OCCUPATION HAZARDS:</p> <p>Write in _____</p>	<p>17. ENVIRONMENT/OCCUPATION HAZARDS</p> <p><i>She was E8 during this pregnancy.</i></p> <p><i>While working during her most recent job during this pregnancy she E9. Her job was E12 and did E13. E14. She did E15 because:</i></p> <p><i>The baby's father was F6 and used F7.</i></p>
<p>18. FAMILY PLANNING:</p> <p>Write in _____</p>	<p>18. FAMILY PLANNING</p> <p><i>She A37.</i></p> <p><i>She remembers feeling that A 28, but A29 consider not continuing her pregnancy. During the three months before she became pregnant she was A 30. A31 or A32. She and the baby's father A 33.</i></p> <p><i>She expects to D6 -7 and plans to D 8. She is D9. She is currently using D 10 as birth control</i></p>
<p>19. OTHER ISSUES:</p> <p>Write in _____</p>	<p>19. OTHER ISSUES:</p> <p><i>Thinking back on the entire experience, things she feels would have made things better for herself H 9. Things she thinks should be done to better help other women and families who experience the death of an infant might be H 10. She would also like to share that</i></p>



Figure 7.
Abstracted/Interview Infant Case Summary

CASE PRESENTATION #

Vital Statistic Infant Death Certificate Information:

Sex: _____

Cause of Death: _____

Lived: _____

Weight: _____

Weeks Gestation: _____

Mother: (age/race/ethnicity/education/marital status) _____

Previous Pregnancies: _____

Father: (age/race/ethnicity/education) _____

Prenatal Care: (began/#visits) _____

Weight Gain: _____

Substance Use: _____

Case Summary Synopsis:

(Information from the medical record)

The mother was (age, gravida, para, race/ethnicity, marital status, education, occupation). She entered prenatal care at____weeks at a (place) with care by (provider) with (# visits). Medical history was significant for:____. Prenatal history included:____. Prenatal referrals included____. She delivered at a level /place at ____weeks gestation by ____delivery method. Apgars were ____, birth weight was____. The infant (was/was not discharged) on day _____. Infant complications included:____. Pediatric history was significant for _____. Pediatric referrals included_____. The infant died at (age) and the events before death included

_____ . An autopsy was/was not done. Findings included:

_____ Bereavement support to family was/ was not done



MEDICAL RECORD

MATERNAL INTERVIEW

I. MEDICAL: MOTHER

Prenatal Medical record:

Mother 7, 3, 4, 5, 6, gravida 14, para 14

Previous Pregnancies: 14 A, B, etc.

LMP: 13

EDC: 13 A by dates:
13 B by sonogram

HIV: 17

Prenatal labs: (Include blood type) 18.

Results unremarkable except for:

Treatment was _____. Repeat at ____ weeks noted.

Pre-existing medical problems: 25

Medications: 24

Problems developed: 26

Nutrition: 29

Pre-pregnancy Weight: 27

Height: 28 B

Body Mass Index: write in

Gained: 28 by 28 weeks.

Identified nutritional factors: 30

Nutritional referrals: 31

Other testing/Procedures:
(include weeks done and any referrals) 38

Hospitalizations: 42

Labor and Delivery Medical Record:

Hospital Level: 1

Time: (write in) 2 Gestational Weeks: (write in)

Reason for Admission:
(write in, include how long with symptoms
of labor, what complaints and how arrived)

I. MEDICAL: MOTHER

She was E 1 and E 2 years old, was born E3, and is E4. She completed E6 and E7.

Her baby was D1 and D1a&b. Prior to this pregnancy she was pregnant D 3, with D 4. D5.

She was A1 weeks when she thought she might be pregnant. She was A2 when she was sure she was pregnant. She was A 20 with her care (Note: expand on issues if not satisfied). During her pregnancy she A 27.

She took A34 special precautions to prevent preterm labor. (A35) She describes her health during her pregnancy as A 36.

She was B 1 on a special diet. Her prepregnancy weight was B2, and she gained a total of B4 and she is B5 tall. She B8. She B3

Labor and Delivery: (Maternal Interview)

She was C1. and C2. She delivered in C3 on C7. Her due date was A3.

She describes her delivery as C4. She spent C 5 nights in the hospital. C 8 - 9 - 10 - 11.

(continued on page 66)



(continued from page 65)

MEDICAL RECORD

Admission History:
write in evaluation at admission,
stage of labor, condition, include BP if has a history
of hypertension, note any abnormalities.

Membranes: 3 - 4 - 5

Monitoring: 10 A-B
Include information of initial fetal
heart rate and also rate prior to delivery.

Problems in labor and delivery: 11

Referrals: 18 - 20

Medications: 17

Anesthesia: 17

Delivery: 8 - 9 - 12 16 -
19 - 25A

Resuscitation: 13,14,15,15B,C

Discharged: 23 - 24 - 25B - 30 -
31 - 32 36

Placental exam:
Write description or include abstracted findings.

MATERNAL INTERVIEW

She says what happened is: Maternal Interview 1 page ii:

2. MEDICAL: INFANT

Newborn Assessment record:

Primary care provider at Delivery: 1

Condition on Admission:

EGA: 2 Weight: 3 Head: 3

Length: 3 Temp: 3

Labs: 4
(also write in H/H, blood type and any other significant find-
ings)

Birth Defects: 5

Morbidity's: 6

Discharge Diagnosis: 8

2. MEDICAL INFANT

*The babies death was explained: (2 on page ii Maternal
Interview)*

*She brought her baby home on Baby 1 A and felt 1 B.
her baby was fed Baby 2, 3 and was put Baby 5.*

*When her baby was at home Baby 13, 17, and 18. She
baby 16.*

*Her baby had Baby 11 and needed Baby 12 A,B,C..
Baby 22 and Baby 23, 24, 25.*

Any Other Information:



MEDICAL RECORD

MATERNAL INTERVIEW

Disposition:	9, 10, 11	
Nutrition:	7	
<i>Newborn Intensive Care Record</i>		
Transfer	1	
Admitting Diagnosis:	2	
Discharge Diagnosis:	3	
Condition:	EGA 4, Heart rate 4,	
Blood Pressure: 4	Temp.: 4	
Weight: 4	Head: 4	Length: 4
Respiratory assistance:	4, 5	
Admission ABG (write in)		
Infection:	6	
Labs: (write in H/H, blood type, etc.)	7	
Birth Defects: (write in treatments, Referrals, medications)	8 9	
Morbidity's: (write in treatments)	9	
Surgery: (include dates/ procedures)	10	
Discharged:	13 14, 15, 18	
Final disposition:	12, 16, 17	
Events preceding death:	11	
<i>Ambulatory Infant Care record:</i>		
Provider	1	
Visits:	2, 3, 4	
<i>Summarize or Repeat for each visit:</i>		
Visits:	1, 2, 3, 4	
Condition:	5, 6, 7	
Immunization:	8	
Presenting Problem:	9	
Tests:	10	

(continued on page 68)



(continued from page 67)

MEDICAL RECORD	MATERNAL INTERVIEW
Diagnosis: 11 A,B	
Treatment: 10	
Follow Up: 13	
Disposition: 14	
<i>Pediatric Emergency Department / Hospitalization</i>	
Admission: 1, 2, 3	
Diagnosis: 4	
Condition: 5	
Discharged: 6, 7, 8, 16	
Medications: 9A &B	
Autopsy: L&D 36, 38, New 13, NICU 22, Ped E/D 17 (Include if offered, by whom and if done or refused)	
Evidence of Injury: Aut 1	
Cause of death: Aut 2	
Culture and Toxicology: write in	
3. PAYMENT FOR SERVICES: MEDICAL	3. PAYMENT FOR CARE
Payer source: PRE 15, L&D 21 NEW 12, NICU 19, Ped E/D 13	PRENATAL CARE : Paid by A 10 and A16. L&D CARE: Paid by C 6. Baby Home: 9, 20, 12B
4. PROBLEMS WITH PRENATAL CARE	4. PROBLEMS WITH PRENATAL CARE
Prenatal care: PRE: First visit 2, 8 13C, at 9, 10, 11 with ___ health care givers.	<i>She A5 received prenatal care as early as she wanted by A4. (If not why, If yes delete.) It A7 was (not) difficult obtaining prenatal care. Her first prenatal visit was at A8 weeks at an A9. She A13 and A14 during the pregnancy. A6</i>
Prenatal Appointments: PRE: 39 - 40 - 41	
L&D 22	<i>She A 15 during her prenatal care and A 19.</i>



MEDICAL RECORD	MATERNAL INTERVIEW
<p>5. PROBLEMS WITH PEDIATRIC CARE - N/A</p> <p>Write in _____</p>	<p>5. PROBLEMS WITH PEDIATRIC CARE</p> <p><i>She took her baby Baby 7, 8, 9. At Baby 10, 14, 15.</i></p>
<p>6. SUBSTANCE USE</p> <p>Substance abuse: _____ Pre 16</p> <p>L&D _____ 29</p> <p>NICU _____ 20</p>	<p>6. SUBSTANCE USE</p> <p><i>She B 15 - B 20 and she B 21 and 22 and she took B 23 - B 24. She A 22 if she was smoking and was A 23 told how it would affect her baby. She A 24 if she was drinking and A 25 how it would affect her baby.</i></p>
<p>7. PRENATAL RISK ASSESSMENT</p> <p>Prenatal risk score: _____ PRE 33, 34, 36, 37</p> <p>Healthy Start: get information from Healthy Start Care Coordination. Include screening and services. _____</p>	
<p>8. INFANT RISK ASSESSMENT:</p> <p>Include information from Healthy Start Screen or medical record documentation _____</p>	
<p>9. SOCIAL SUPPORT</p> <p>Psychosocial Assessment/ Social Issues: _____ PRE 19, 20, 21, 22, 23;</p> <p>L&D Psychosocial: _____ 27 - 28 - 29 -</p> <p>NICU _____ 20</p> <p>Ped E/D: _____ 10, 12</p>	<p>9. SOCIAL SUPPORT</p> <p><i>If a problem had come up in the 12 months before the baby was born H4 would have helped. The baby's father completed F 1 and F2 of education and is F3 and F4. She describes her relationship with the baby's father as F8 and she was F9 satisfied with his contributions financially. During the pregnancy the baby's father F10. She describes her relationship with the father now as F11.</i></p>
<p>10. HOMELESS/TRANSIENT</p> <p>Pre _____ 21</p> <p>L&D _____ 29</p> <p>NICU _____ 20</p> <p>Ped E/D : _____ 10</p>	<p>10. HOMELESS/ TRANSIENT</p> <p><i>She felt G1 satisfied with her overall living situation. She G5 a G6 and paid G7 each month. She G9. She G8 in the past year. There was G10 affording a place to stay or when she couldn't afford the rent or mortgage and G11 from her home and G12.</i></p> <p style="text-align: right;"><i>(continued on page 70)</i></p>



(continued from page 69)

MEDICAL RECORD	MATERNAL INTERVIEW
<p>11. POVERTY</p> <p>Pre 21, L&D 29, NICU 20, Ped E/D 10</p> <hr/> <p>Include Additional Economic Services: Use if information regarding WIC, Medicaid, AFDC, etc. is available.</p> <hr/>	<p>11. POVERTY</p> <p><i>During her pregnancy she felt she B9. She B 10 cut down on the amount of food she bought. There was B11. Sources of family income were G2 and her estimated yearly income was G4. Before the baby died, she G 13 worry about not having enough money from one month to the next.</i></p>
<p>12. MENTAL HEALTH/ STRESS</p> <p>Pre 21, L&D 29, NICU 20</p> <hr/> <p>Ped E/D 10</p> <hr/>	<p>12. MENTAL HEALTH/ STRESS</p> <p><i>During the 12 months before delivering her baby H 1-2-3. During the pregnancy the father experienced F 10.</i></p> <p><i>In the last month she has H 5 felt good about her ability to handle her personal problems and that difficulties H 6 were piling up so high that she could not overcome them. She has H7 felt depressed, down, or blue. Since her baby died she and her partner have H8 received counseling or joined a support group for parents who have lost a baby.</i></p>
<p>13. FAMILY VIOLENCE/NEGLECT</p> <p>Pre 21, L&D 29, NICU 20, AMB 7, Ped E/D 10</p> <hr/>	<p>13. FAMILY VIOLENCE/ NEGLECT</p> <p><i>H 1, 2,3</i></p>
<p>14. CULTURE</p> <p>Write in</p> <hr/>	<p>14. CULTURE</p> <p><i>E5, F5</i></p>
<p>15. TRANSPORTATION</p> <p>Write in</p> <hr/>	<p>15. TRANSPORTATION</p> <p><i>She traveled by A11 to get there and it took A12. (Also A17, A18 if used). E 10, 11.</i></p>
<p>16. PROVISION/ DESIGN OF SERVICES</p> <p>Documented education: Pre 35, Education not discussed: Pre 35, L&D 26, NICU 18, Ped ER16</p> <hr/> <p>Education:</p> <hr/> <p>Bereavement: L&D 34 35 37, NEW 14, PDER18, NICU23</p> <hr/> <p>Referrals: Pre 32, L&D 33, NICU 21 PED E/D 11</p> <hr/>	<p>16. PROVISION/ DESIGN OF SERVICES</p> <p><i>Education discussed with her during her prenatal care included A21. She was asked A26 and she attended A27. Nutrition B6 discussed with her. She B7.</i></p> <p><i>She B12 WIC. Advice given at WIC included B13. and it B14 to get WIC vouchers.</i></p> <p><i>She was taught Baby 12 C. She received baby 21.</i></p>



MEDICAL RECORD

MATERNAL INTERVIEW

17. ENVIRONMENT/OCCUPATION HAZARDS

Write in

18. FAMILY PLANNING

Write in

19. OTHER ISSUES:

Write in

17. ENVIRONMENT/OCCUPATION HAZARDS

She was E8 during this pregnancy.

While working during her most recent job during this pregnancy she E9. Her job was E12 and did E13, E14.

She did E15 because:

The baby's father was F6 and used F7.

She returned to baby 6, A&B. Her baby was Baby 4.

18. FAMILY PLANNING

She A37.

She remembers feeling that A 28, but A29 consider not continuing her pregnancy. During the three months before she became pregnant she was A 30, A31 or A32. She and the baby's father A 33.

She expects to D6 -7 and plans to D 8. She is D9. She is currently using D 10 as birth control.

19. OTHER ISSUES:

Thinking back on the entire experience, things she feels would have made things better for herself H 9. Things she thinks should be done to better help other women and families who experience the death of an infant might be H 10. She would also like to share that:

CHAPTER 6

Self-Care for the FIMR Interviewer

“It is one of the most beautiful compensations of life that no man help another without helping himself.”

–Ralph Waldo Emerson

Interviewers must be prepared for their own grief response to the interview as well as that of the mother. Listening to parents talk about their baby’s life and death has an impact on the interviewer and can lead to emotional exhaustion. Some interviewers report changes in mood described as feelings of anxiety, irritability, depression, sadness, and moodiness for a few hours after the visit. One interviewer commented:

“I always feel better after I have a good cry” (12).

Another interviewer experienced exhaustion, the kind that comes after an intense period of listening and reflection. The interviewer’s grief is real and should not be minimized.

“I was saddened for the devastating loss of this young mother but I felt good about the visit. I felt I was able to help her.” (13).

Before the first home visit, every prospective interviewer should learn about healthy coping strategies and make a firm commitment to practice those that work for her or him. Some examples of these strategies are shown in Figure 8. When working with bereaved mothers, the interviewers are more effective when they use strategies that help them cope with their own reactions to loss. Suggestions for coping and self-care include but are not limited to spending time with family and friends, meditating, practicing relaxation techniques, or exercising.

According to Daniel Timmel, LCSW, former technical consultant to Maryland FIMR Programs, FIMR interviewers need to take care of themselves in order to do the very best for the mothers they interview (14).

“During a home visit you may be the only person in weeks who has used the baby’s name or allowed the parent to discuss the loss. The pictures come out, the tears; you start to get a lump in your throat yourself. Your impulse is to try and relieve their sadness. You have to recognize that you can’t fix their grief but can be a supportive listener and can help arrange for resources.”



**“May You be Strengthened
by Yesterday’s Rain
Walk Straight in
Tomorrow’s Wind
And Cherish Each Moment
of the Sun Today.”**

–Ojibiwa Prayer



Figure 8. Coping With Your Response to the FIMR Home Interview/Taking Care of Yourself

Learning to cope with your own response will help keep you balanced and make you a better resource for the families you work with.

To replenish yourself

- Take responsibility for your personal well-being.
- Make professional time limitations and stick to them.
- Actively grieve your own losses.
- Learn to receive as well as give.
- Offer support to each other as FIMR home interviewers.

To preserve yourself as an effective helper

- Identify six things you do that you make you healthy and happy.
- Identify six things you do that are inclined to make you tired or depleted.

To be a healthy caregiver

- Know both your strengths and your limitations.
- Be aware of your reactions and emotions and recognize when they change from positive ones to negative ones.
- Know that you contribute, but that others can live without you.
- Know when you need to say “no.”
- Take responsibility for your own needs before seeing to another.
- Follow your own personal joy; do the things that make you happy.

Adapted with permission from the California Department of Health Services. Maternal and Child Health Branch. The California SIDS Program. *A Practical Guide to the SIDS Home Visit*. Fair Oaks, CA: The California SIDS Program, 2001 p4–1.

Home interviewers often have to deal with unhappiness in their own lives at the same time they are in contact with the mother and other family members. Interviewers who are pregnant or parenting infants can have an intense personal response to the mother’s experience. Some home interviewers might be dealing with sadness about the death of a relative or friend at the same time they are trying to provide grief support to a mother. Adequate supervision and discussions with peers can provide an opportunity for interviewers to acknowledge their sorrow and help each other in their efforts to assist bereaved mothers.

The Centre for Living with Dying offers the following insights (15):

“Remember, when you are journeying with people in pain, you step off your road and onto their road when you are supporting them. When you are complete for the moment, it is important to step back onto your road and claim the backpack of your life, with all its frustrations, joys and love. When you find yourself over-identifying with the person you are supporting, it sometimes helps to begin to notice all the physical ways in which you are different from them—eyes, hair, body type, personality, face, etc.... This is a quick way to disconnect. Remember, we have no right to “rob” anybody of their pain or their life journey. For whatever reason, which we may never understand, they are living their own truth in this moment of time. We can walk beside them and share with them our unconditional, non-judgmental support.”

Every FIMR home interviewer should develop a network of much-needed support. Although the interviewer must maintain strict confidentiality and may not share specific information from the interview, it may be helpful to talk with interviewers from other FIMR programs to share feelings and provide mutual support. Interviewers can establish linkages with community bereavement professionals such as SIDS counselors or hospice service providers. During debriefing sessions with the FIMR coordinator, the interviewer can discuss the mother’s experiences and responses in detail. One interviewer commented:

“I found it helpful to vent my own feelings; to be reassured that something had been accomplished and that much of the family’s behavior was normal” (16).

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Appendices



Appendix A: Field Safety

To ensure safety, each and every FIMR home visitor must be constantly alert and aware of her or his surroundings. No matter what part of the county, the setting (rural, suburban, or city), or the socioeconomic status of the neighborhood, always adhere to the general tips that follow.

Dress Sensibly

1. Wear comfortable shoes that are easy to walk or run in, if necessary.
2. Wear clothes that make it easy to move.
3. Select bright-colored clothing with pockets.
4. Don't carry a purse.
5. Don't wear ostentatious jewelry, such as diamond or gem rings, large, expensive or dangling earrings, big pins, etc.
6. Carry a noise-making device, such as a whistle.
8. Carry two sets of car keys. Put one set in your pocket and the other concealed and taped inside a notebook.
9. If you see someone tampering with the vehicle, DO NOT try to stop them. Call 911 as quickly as possible.

Car Safety

1. It is suggested that a resource such as AAA be available in case the car breaks down or you lock yourself out of your car.
2. Carry an emergency spare tire in the car.
3. Be sure the gas tank is full.
4. Always carry a cell phone to call for help if needed.
5. Drive with the car doors locked and, if possible, the car windows up.
6. Always lock the car when you get out.
7. Always carry car keys in your hand when you are leaving the office to go to your car, from your home to the car, or from a home visit to the car.
5. If the home is in an unfamiliar location, try to find a co-worker who may be familiar with the location to brief you on the neighborhood.
2. Ask for precise driving directions, consult a map before leaving the office, or print out driving directions from the World Wide Web.
3. Let your office know that you will call at scheduled times.
4. Arrange your work schedule so that home visits are usually early in the day so you will not be leaving a home visit after dark.
5. Carry minimal amounts of cash, but do carry some.
6. Fit all of the needed interview forms into a binder or notebook before you leave the office, thus obviating any need to return to your car.
7. Lock your purse in the trunk of your car before leaving the office.
8. Do not carry your home address with you.

In the Home

1. Be polite. Remember that you are a guest in their home.
2. Clearly say your name, the agency you represent, and why you are there. Give them your business card and show the mother your official identification.
3. Ask to be seated. Choose a hard chair that is easy to get out of, if possible.
4. Try to sit so your back is to a solid wall, not to an unknown space. Sit close to the door, if possible.
5. Stay alert when you are in the home and be aware of other people in the dwelling and traffic in and out of the home.
6. Use the same principles inside the dwelling as you have used outside to get there.
7. Do not assume an animal won't hurt you despite what the owner says. If you feel uncomfortable, ask the owner to restrain or remove the animal.
8. Do not go into a dark room, basement, or attic first. Have the mother go first and turn on the light. Follow her, never lead, even if you have been to their home before.

Leaving the Home

1. Get your keys out before you leave the home. Walk briskly to your car, unlock the door, get into the car quickly, and lock the door.
2. Even though your own physical safety is important, don't forget there may be small children or animals playing by or under your car. Be sure to check both sides of your car before moving from your parking space.
3. If someone leans up against your car, don't be rude and don't be intimidated. Quickly lock the door and leave.
4. Watch for cars following you when you leave. Never stop if someone tries to block you or indicates they want you to pull over, but proceed to a well-lighted business or the nearest firehouse or police station.

In General

ALWAYS TRUST YOUR GUT. If something feels unsafe to you, it IS unsafe.

Adapted from: Field nursing safety: a guide to identifying steps to take in order to minimize potential hazards of conducting a home visit. Multnomah County, Oregon Department of Human Services and Health Division, January 1991.

Appendix B: Resources for FIMR Home Visitors and Families

Suggested Reading

- American College of Obstetricians and Gynecologists. *Grieving: A Way to Heal*. ACOG Patient Education Pamphlet AP078. Washington, DC: ACOG, 1996
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Web Site Resources for Families

A Place to Remember

<http://www.aplacetoremember.com/aptrfront.html> A Place to Remember provides support materials and resources for those touched by a crisis in pregnancy or the death of a baby. It offers an extensive annotated bibliography. It was started by a bereaved parent who is a publisher/writer.

Center for Loss in Multiple Birth (CLIMB)

<http://www.climb-support.org/> CLIMB is a resource for loss of twins or multiples.

Centering Corporation

<http://www.centering.org/> Centering provides a non-profit network for distributing supportive grief literature from other sources. They have a wide variety of grief literature available for children and adults.

The Centre for Living with Dying

<http://www.TheCentre.org> The Centre is the largest bereavement support agency of its kind in the United States and has served over 800,000 people. The Centre provides services to any person faced with a life threatening illness, grief, loss or trauma. Clients receive emotional support either through 1 with 1 support or a grief group.

The CJ Foundation for SIDS

<http://www.cjsids.com/index.htm> The CJ Foundation for Sudden Infant Death Syndrome is a nationwide voluntary health organization dedicated to recognizing the special needs of the SIDS community through funding SIDS research and support services.

Compassion Books

<http://www.compassionbooks.com/> Resources are listed to help children and adults through serious illness, death, loss, and grief and bereavement.

Appendix B: Resources for FIMR Home Visitors and Families (*continued*)

The Compassionate Friends

<http://www.compassionatefriends.org/> The Compassionate Friends is a national nonprofit, self-help support organization that offers friendship and understanding to families who are grieving the death of a child of any age, from any cause. The site includes links to other grief resources, local chapter meetings, brochures, and information for children.

GriefNet

<http://rivendell.org/> GriefNet is an Internet community of persons dealing with grief, death, and major loss. They have 37 e-mail support groups and two Web sites. The companion site is KIDSAID, which provides a safe environment for kids and their parents to find information and ask questions. An annotated bibliography is available.

MISS: Mothers in Sympathy and Support

<http://www.misschildren.org/> MISS is a nonprofit organization committed to providing immediate and ongoing psychosocial support after the death of a baby due to stillbirth, neonatal death, or SIDS, or any child's death.

Pregnancy and Infant Loss Center

www.pilc.org The Pregnancy and Infant loss Center provides information, referrals, and resources to parents coping with the loss of a pregnancy or infant death.

SHARE Pregnancy and Infant Loss Support, Inc.

<http://www.nationalshareoffice.com/> SHARE is a resource center for parents who have experienced the loss of an infant through miscarriage, stillbirth, or newborn death. SHARE also provides information, education, and resources on the needs and rights of bereaved parents and siblings.

SIDS Alliance

<http://www.sidsalliance.org/> The Sudden Infant Death Syndrome (SIDS) Alliance is a national, nonprofit, voluntary health organization dedicated to the support of SIDS families, education, and research. Peer support groups are available in some states.

Sudden Infant Death Syndrome Network

<http://sids-network.org> Sudden Infant Death Syndrome Network, Inc., is a nonprofit, voluntary agency. This Web site has online SIDS information and links to other SIDS sites.

Infant Loss Literature for Families

The following are some suggested pamphlets for families. Please refer to the Web sites listed in “Web Site Resources for Families” for additional references.

Brochures by The Compassionate Friends (TCF) are very economical at 20 cents each or a package of 100 for \$15. These can be reviewed on the Internet at <http://www.compassionatefriends.org/brochures.shtml>. TCF allows single copies to be printed. Note that two brochures are in Spanish.

- Understanding Grief When a Child Dies
Spanish version: Entendiendo el pesar...cuando muere un hijo
- Caring for Surviving Children
Spanish version: La crianza de los hijos sobrevivientes
- Stillbirth, Miscarriage and Infant Death

Longer references from The Compassionate Friends:

- The Grief of Parents...When a Child Dies (\$3.00)
- When a Baby Dies (\$2.00)

The following multicultural brochures are available in English and Spanish from the Massachusetts Center for Sudden Infant Death Syndrome, Boston Medical Center, One Boston Medical Center Place, Boston, MA 02118, (617) 414-7437.

READ THIS—if you want to feel good and look good before and after pregnancy (\$1.50 each)

ABOUT YOUR BABY—help your baby grow and be happy, safe and healthy (\$1.50 each)

WHEN A BABY DIES—grieving, healing, understanding feelings (\$1.50 each)

SIDS: A brochure for American Indian families (English only, \$1.00 each)

The following is a free publication for interviewers and may be appropriate for some parents. It is available at no charge from the National SIDS Resource Center at <http://www.sidscenter.org/>:

The Death of a Child, The Grief of the Parents: A Lifetime Journey

Web Resources for Home Interviewers

American Academy of Pediatrics (AAP)

<http://www.aap.org/> The AAP provides professional and community health-related information. Books and pamphlets are available for purchase.

Association of Death Education and Counseling (ADEC)

<http://www.adec.org/> ADEC is a multi-disciplinary professional organization dedicated to promoting excellence in death education, bereavement counseling, and care of the dying.

Association of SIDS and Infant Mortality Programs (ASIP)

<http://www.ASIPI.org> ASIP is for health and human service providers committed to bereavement support and risk reduction activities. Materials are available for purchase.

Back to Sleep (BTS)

<http://www.nichd.nih.gov/sids/> The BTS campaign is named for its recommendation to place healthy babies on their backs to sleep to reduce the risk of SIDS. The BTS campaign Web site provides up-to-date information on SIDS research and campaign materials at no charge.

Centers for Disease Control and Prevention (CDC)

<http://www.cdc.gov/> The CDC is the lead federal agency for protecting the health and safety of people at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships.

Consumer Product Safety Commission (CPSC)

<http://www.cpsc.gov/> An independent federal regulatory agency, CPSC works to save lives and keep families safe by reducing the risk of injuries and deaths associated with consumer products.

Hospice Foundation of America (HFA)

<http://www.hospicefoundation.org/> HFA works to educate professionals and the families they serve in issues relating to caregiving, terminal illness, and loss and bereavement.

March of Dimes (MOD)

<http://www.modimes.org/> MOD's goal is for all babies to be born healthy. They have publications available to promote this mission, as well as bereavement publications.

The National Center for Cultural Competence (NCCC)

<http://www.georgetown.edu/research/gucdc/nccc/> The mission of the NCCC is to increase the capacity of health care and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems.

National Center for Education in Maternal and Child Health (NCEMCH)

<http://www.ncemch.org/> NCEMCH provides national leadership to the maternal-child health community in program development, policy analysis, and education.

National Fetal and Infant Mortality Review Program (NFIMR)

<http://www.acog.org> NFIMR has publications and resource materials designed to support and enhance FIMR programs. It is funded by the Maternal and Child Health Bureau (MCHB) under the U.S. Department of Health and Human Service's Health Resources and Services Administration.

National Healthy Mothers, Healthy Babies Coalition (HMHB)

<http://www.hmhb.org/> The mission of HMHB is to improve the health and safety of mothers, babies, and families through education and collaborative partnerships of public and private organizations.

National Institutes of Health (NIH)

<http://www.nih.gov/> NIH is one of the world's foremost medical research centers and the federal focal point for medical research in the United States. Its mission includes supporting research and fostering the communication of medical information.

National Sudden Infant Death Syndrome Resource Center

<http://www.sidscenter.org/> Information services and technical assistance on SIDS and related topics are provided. This MCHB site also has a variety of publications including annotated bibliographies and referrals to resources.

Other Printed Materials

California SIDS Program, 3164 Gold Camp Drive, Suite 220, Rancho Cordova, CA 95670-6052. (916) 536-0146 A variety of printed literature for families and professionals and the manual titled A Practical Guide to the SIDS Home Visit.

Notes

Notes

To learn more about the fetal and infant mortality review process, please write, fax or call:



THE NATIONAL FETAL AND INFANT
MORTALITY REVIEW PROGRAM

THE AMERICAN COLLEGE OF OBSTETRICIANS
AND GYNECOLOGISTS

Mailing Address: PO Box 96920, Washington, DC 20090-6920
Fax: 202-484-3917 • Phone: 202-863-2587 • E-mail address: nfimir@acog.org • Web Site: www.acog.org/goto/nfimir