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Navigating care after a baby dies: a systematic review of parent experiences with health providers

KJ Gold[1,2]

[1]Department of Family Medicine, University of Michigan Health System, Ann Arbor, MI, USA and [2]Department of Internal Medicine, Robert Wood Johnson Clinical Scholars Program, University of Michigan Health System, Ann Arbor, MI, USA

Introduction: Health care providers are on the front lines of care when a baby dies, but there is no consensus about which behaviors are most helpful or harmful for families.

Materials and Methods: This systematic review of more than 1100 English-language articles from 1966 to 2006 addressed fetal and early infant loss and extracted information about interactions with health providers.

Results: Sixty-one studies, covering over 6000 parents, met criteria. Nurses were generally viewed as more emotionally supportive than physicians. Parents valued emotional support, attention to mother and baby and grief education. Avoidance, insensitivity and poor staff communication were the most distressing behaviors encountered.

Discussion: Interactions with health providers has profound effects on parents with perinatal losses. Grieving parents perceive many behaviors to be thoughtless or insensitive. Physicians and nurses may benefit from increased training in bereavement support.
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Keywords: perinatal death; fetal death; stillbirth; infant death; bereavement; attitudes of health professionals

Introduction

Parents usually experience late pregnancy and infant loss as an intensely painful and traumatic event. In the last few decades, providers have recognized that the death of a fetus or young infant can cause prolonged or complicated bereavement for many parents.[1–4] Health care providers are on the front lines, offering bereaved families comfort and support, helping parents say goodbye to their deceased infant and educating about the grieving process. Interviews with parents have demonstrated that health care providers can make families feel either supported or helpless after their infant or child dies.[2,5–7]

A fetal or infant death is a traumatic loss – often sudden and unexpected, sometimes forcing families to integrate the almost simultaneous experiences of birth and death. Intrusive thoughts and avoidant behaviors – once thought to be associated only with exposure to life-threatening traumas like war or assault – now are recognized as common symptoms in acute grief reactions.[8,9] After experiencing or witnessing physical trauma, people typically draw memories and vivid images from the high-stress periods of the trauma. For example, soldiers returning from battle may not recall mundane events but may have intrusive flashbacks of a specific battle or explosion. Similarly, stories that parents tell about perinatal loss virtually always include details about the actual time and experience of death, consistent with the idea that birth and death are times of great emotional arousal.[10] Like for other trauma survivors, parents interviewed years and even decades after a child's death report a surprising level of detail regarding the event and can often retell the story of the loss, comments people made and upsetting aspects of their experience.[6,11–13] During these high-stress times, seemingly benign mis-steps by a health care provider may be engrained in a bereaved parent's memory and replayed over and over in the years to come.

Many individual studies have asked parents to describe or rate their interactions with health care providers after perinatal loss, but no systematic review of this literature could be identified. Therefore, this review set out to systematically collect and summarize all articles containing data on how bereaved parents recalled and perceived their interactions with health care staff (see Supplementary Table 1). The interactions were then categorized to determine which behaviors and comments parents perceived as most helpful and which were most distressing.

Materials and methods

Data sources

The review focused on care of patients following pregnancy and early infant loss for the 40-year period from 1966 to mid-2006 using MEDLINE, PREMEDLINE, CINAHL, EMBASE, PSYCHINFO and SOCIOFILE. Search terms focused on pregnancy loss and fetal death, including: *neonatal death, perinatal death, fetal death,*

Correspondence: Dr KJ Gold, Department of Family Medicine and Department of Internal Medicine, University of Michigan Health System, 6312 Medical Science Building 1, 1150 W. Medical Center Drive, Ann Arbor, MI 48109-0604, USA.
E-mail: ktgold@umich.edu
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pregnancy loss, stillbirth, sudden infant death, infant mortality; grief (*grief, bereavement*) and adaptation (*adaptation-psychological, attitude of health personnel, parents-psychology, stress-psychological, attitude to death).* The search was initially performed in September 2005 by the author and an experienced medical librarian and was repeated in February 2006 to update the list of articles. References from review articles were scanned to identify additional studies. This review generally adheres to the reporting strategy recommended by the Meta-analysis of Observational Studies in Epidemiology (MOOSE).[14] However, as the topic primarily encompasses qualitative studies, not all MOOSE recommendations were feasible, and researchers believed that meta-analysis of the data would not be valid given the enormous variations in methodology among studies and the predominance of qualitative reports.

Study selection

Inclusion criteria included studies that examined unplanned losses in the second or third trimester of pregnancy (14 weeks and beyond) or the first month of infancy. Most losses in this period will require hospital care and interactions with the inpatient health care system whereas miscarriages in the first trimester are typically managed in an outpatient setting or may not require medical attention at all. Studies which described losses at multiple stages of pregnancy were included only if 'ineligible' losses which did not meet criteria could be separated from the other losses or if ineligible losses represented less than 50% of the deaths described. In this paper, 'perinatal death' refers to losses between 14 weeks and 1 month of life, 'stillbirth' is used to describe a loss at or after 20 weeks gestation but before birth, and 'infant loss' is used for a death in the first month of life.

Articles were required to involve care in the United States; be written in English; have a minimum of at least four participants (to avoid small case reports); include a full paper; and, most importantly, to contain some type of direct patient input such as survey data, interviews, focus groups, or program or chart reviews. As the focus of this review was on parental experiences, review articles without direct patient data, articles providing advice from experts, first-person case studies, or research that did not address patient care were all excluded. International articles were searched and reviewed; however, only American studies were included in this summary, as cultural norms vary considerably, and a nation's cultural context and individual health care system are likely to exert a strong influence on patient–provider interactions.

Results

A total of 1114 articles were identified by the initial search strategies (Figure 1). For 419 articles, the abstract contained sufficient information to determine that the study did not meet inclusion criteria. Of the 695 manuscripts that underwent full review, 124 met all inclusion criteria and 60 of these described care in the US (Figure 1). The US studies included more than 6200 parents of which an estimated 10% were fathers and 90% mothers (a few articles referred to 'couples' or 'parents' without quantifying the gender of each participant, and not all studies actually identified the total number of subjects). Race or ethnicity was indicated in half of the studies, and typically was predominantly white. Marital and SES status were varied and encompassed a broad spectrum. Seven of the studies were published in the 1970s, 16 in the 1980s, 21 in the 1990s and 16 in the year 2000 and beyond.

Comparing nurses, physicians and hospital staff

Two-thirds of the studies ($n = 37$) contained parental views specifically about interactions with caregivers and these were evaluated first to determine whether parents had different interactions with different types of hospital providers.

Nurses were generally perceived as the care provider most likely to provide emotional support, and they received the highest satisfaction ratings of all providers.[15–18] Twenty-three articles mentioned something positive about the nurses or nursing care. In one study, all the parents had at least some favorable comments about their caregivers and most often described such experiences as being with nurses.[19] In another report, 86% of parents stated that the chance to discuss their feelings with the nurse was helpful.[20] However, these positive reviews were not universal, and parents in several studies expressed disappointment about interactions with nursing staff.[22,23] For example, in one project, only half of parents reported that they believed the nurse listened to them; in another, only half of nurses were described as supportive; and in a third, 18/28 parents described their nurses as cold or neutral.[24–26]

Twenty-five articles mentioned at least something positive about experiences with physicians, but doctors were typically rated as much less helpful and supportive than nurses. No mother mentioned a physician as a source of support in one study, and in

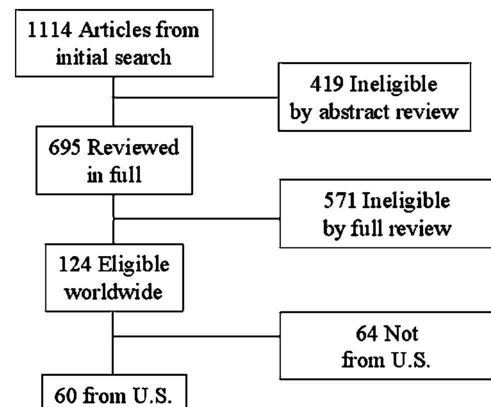

Figure 1 Systematic selection of articles.

a second, only half of patients reported discussing their feelings about the loss with a physician.[15,27] DiMarco *et al*. (2001) found physicians were rated as the least helpful of any type of staff member.[22] However, not all studies were as negative. One researcher found a third of parents reported a generally positive relationship with their physician and another third reported a mixed positive and negative relationship.[25] Physicians were described as cold or neutral by 15/28 parents in one study, slightly better than nurses but still a poor rating.[26]

Hospital staff in general also received mixed reviews. One researcher noted hospital staff were described as just the third most helpful part of bereavement care, preceded both by support groups and mourning rituals.[28] Covington and Theut (1993) reported 2% of parents had only positive interactions with staff whereas 22% reported only negative reactions.[29] Parents in a 1970s study stated they saw staff attendants as cold or neutral over half the time.[26] Similarly, a third study concluded that parents described hospital staff as helpful most or almost always 46% of the time but unhelpful 35% of the time.[30] On the other hand, some reports were more favorable. Lasker and Toedter (1994) found 64% of parents very satisfied with the hospital staff, 36% satisfied and only 21% dissatisfied.[31] Similarly, Pector (2004) noted that parents who had infants in the Neonatal Intensive Care Unit (NICU) before death said 49% of staff remembered or acknowledged their loss and 76% reported they had been given support for their grief.[32]

In summary, parents had mixed experiences with their care providers with a high number expressing discomfort or dissatisfaction with specific interactions or insensitive behaviors and comments. Although nurses tended to be rated as more supportive than physicians or staff members, in several studies a large number of parents experienced poor support from their nurses as well.

Key areas of parent dissatisfaction

In many situations, parents identified at least one specific behavior or comment that was particularly offensive or upsetting to them. Although families in several studies were interviewed months and years after their losses, these negative interactions remained prominent in their memories of care.

Parents in five studies reported that lack of communication between staff members about the death was an egregious error. Many parents expressed resentment when staff members seemed to have forgotten a baby's death or made thoughtless comments,[32–34] for example, when at a post-partum visit, after an infant died at 3 weeks of age, the obstetrician asked the mother how the baby's health was currently.[35] Another mother described multiple staff members, including nurses and a chaplain, coming cheerfully into her hospital room after delivery, apparently unaware of her loss.[36] Some parents were upset by nurses or aides who offered to bring a baby in for breastfeeding despite the fact that the babies were confined in the NICU and not able to nurse.[37]

Next, families in 12 studies complained that doctors and nurses had avoided them or tried not to participate in their care after a perinatal death. One mother recalled that her obstetrician avoided seeing or talking with the family after the day the baby died.[38] A mother who had lost her baby more than 20 years previously recalled her 'obstetrician's silence [as] the most deafening.',[34] (p 251) Parents found it uncomfortable to have nurses who seemed to avoid the room and frequently left the family alone.[23,25,32,33,38] Others reported anger at physicians and nurses who were late or even absent for the delivery of a stillborn infant.[33]

The most frequent criticism of caregivers was lack of emotional support or frank insensitivity; such complaints were voiced by parents in 25 studies. One mother who complained of pain while breastfeeding her one surviving twin reported that the nurse responded, 'Well, maybe that is why God took the other baby from you, because you couldn't handle nursing two of them like this.',[39] (p 36) Parents were also distressed when staff members treated deceased infants carelessly. One mother remembered the birth of her stillborn baby: 'they took him out and laid him on a metal table and just left him there'.[36] (p 113) Another recalled a nurse bringing in a biohazard container for the delivery.[32] Sychowski (1998) describes a mother distressed to see her deceased baby placed directly into a bucket after delivery.[39]

In seven studies, parents expressed blame of caregivers. Years after a loss, many parents still held medical staff responsible for the death of their baby, although these feelings appeared to soften over time.[40,41] In one paper, 68% of parents reported still feeling angry at health professionals for the death after 3 months, but this figure had dropped to 37% by 9 months.[42] Several parents believed medical staff had minimized concerns expressed by the parents during pregnancy; the families believed that if they had been taken more seriously, their infant might have survived.[29,31,34,36] Several low-income parents reported that they had been treated unequally based on their finances.[17] As one mother lamented after her child died in the NICU, 'if I had a better insurance, they would have put their heart and soul into it and I feel they didn't.',[17] (p 601) A few parents with losses decades previously told stories of doctors who admitted blame – but as one mother explained, 'no one sued doctors then'[43] (p 85).

In summary, families expressed general dissatisfaction with care when staff were unaware of their loss or when providers were perceived as avoiding the family, lacking in emotional support, or making thoughtless comments. Years later, parents often still felt the medical providers were responsible for the perinatal death.

Interactions helpful to parents

In contrast to the behaviors that upset parents, families also recalled caring comments or actions of health care providers that had improved their hospital experience. These tended to fall into one of three realms: emotional support, physical support and education.

Parents in 18 studies described their appreciation for caregivers who provided strong emotional support by taking time to talk with the family and staying with them. Nurses who gave parents permission to cry, who used humor appropriately and who seemed to go out of their way to spend extra time with the family were viewed as particularly supportive.[16,30,44] Many parents felt their nurses had given them special attention; some identified this as extra emotional or spiritual support whereas others saw it as additional time or care beyond the usual tasks.[17,20] Several parents commented that when caregivers were themselves tearful, it felt honest and genuine and the tears seemed appropriate.[16,32] Lemmer (1991) found mothers commented favorably on nurses who treated them as parents despite the loss and who talked openly about the baby and the birth after the baby's death.[18]

Physical care and tangible help from nurses was identified as very important to grieving families in 10 studies. Parents frequently described nurses bending hospital policies to accommodate them, such as expanding visiting hours or allowing children on the wards.[16,20,24,44] Families appreciated nurses who took care to provide special photos or mementoes of the baby or who helped them create memories of their baby.[17,18] Nurses who attended to the physical needs of mothers after delivery, including small tasks such as brushing a mother's hair or holding her hand, were also seen as supportive.[18,33] Parents were acutely aware of how the nurses treated their babies, and nurses who dressed or bathed a deceased baby in a caring manner or treated the body respectfully were viewed favorably by surviving family members.[18,33]

In addition, parents in nine studies reported valuing education from health providers. Physicians who offered medical information as well as counseling or education about what to expect in the grieving process were rated as highly competent.[45] Parents generally wanted to know the cause of death and although they did not always recall the details, they did remember if the physician had sat and talked with them about this topic.[30,44] Parents made note of staff who helped keep the family informed and who provided information about treatment plans or prognosis of critically ill infants.[16,18,38,44] Families also liked providers who they felt gave honest answers and appreciated health teams who provided them with consistent information, though parents often reported wanting even more information and explanations.[16,31,46] Finally, Wing (2002) described a perinatal grief program with multiple components and found, not surprisingly, that there was a correlation between the overall number of bereavement services given to parents and their general level of satisfaction with care.[46]

In short, bereaved parents were most appreciative of actions that demonstrated emotional support from providers and showed attention to the physical needs of the mother and baby. They also viewed education on the grief process, direct communication about the baby's status and cause of death and consistent information from all the team members as valuable services from their health care providers.

Discussion

Although the rate of fetal and infant death has slowly declined over the years, these losses still affect up to one in 50 births. How providers assist grieving parents in coping with this traumatic event appears to have an important impact on how parents experience and remember their loss and may have significant effects on their healing. Parental views on useful types of care may also provide guidance to physicians and nurses who assist patients with other types of traumatic loss such as the death of an older child or an unexpected death of an adult.

This review sought to evaluate systematically parent experience with health care providers after a perinatal loss and to identify common themes of behaviors that were viewed as helpful or not helpful to parents. In general, physician interactions were viewed less favorably than those of nurses. Similarly, Weinfeld's (1990) review of a community hospital found that nurses were much more likely than physicians to encourage contact with the deceased infant (100% nurses versus 15% of physicians), take photographs (100 versus 0%) and provide emotional support (90 versus 35%).[21] Parents identified the most distressing behaviors as including interactions with staff who were completely unaware of the event, and avoidance, insensitivity, or lack of emotional support from providers. Actions such as providing extra attention and emotional caring, physical attention to both mother and baby and information about the birth event and outcomes were seen most positively by parents.

The interactions which patients valued often involved only a small effort from the health care providers (Table 1). Helpful providers were described as being comfortable talking about the birth and loss and were felt to educate parents about what to expect as they navigated through their grief. Treating both mothers and their deceased infants with respect was crucial. These behaviors are not specific to perinatal grief; Widger (2004) has identified such actions as important in the general palliative care of children.[47]

It is worrisome that even as medical schools have increased their focus on the physician–patient interaction and have promoted empathetic models of practice, patients continue to view doctors as far less supportive than nurses. This review showed an increased focus on bereavement interventions from the 1970s to the 2000s, but there was no similar trend toward greater provider compassion or support.

In addition, far too many providers are uncomfortable with death and bereavement – particularly for infants and children. Some loss guidelines specifically state that provider guilt and anxiety have the potential to interfere with care and recommend bereavement training for health care professionals.[48–51] In one hospital, grief coordinators discovered so much discomfort and anxiety among the staff about dealing with perinatal death that they had to increase education and training programs to help the

Table 1 Provider behaviors viewed most favorably by parents after perinatal death

Offering emotional support
Stay with the family and spend extra time with them as much as practical
Talk about the baby by name
Allow parents to grieve or cry
Be sensitive to comments that could be perceived as trite or minimizing of grief
Return to see family on multiple occasions, if possible
Attending to physical needs of parents and baby
Continue routine post-partum nursing and medical care for mother
Treat infant's body respectfully
Consider dressing, bathing, or wrapping infant as for a live baby
Be flexible about hospital policies that may not be appropriate for bereaved families
Help parents create tangible memories of their infant
Educating parents
Communicate loss to all staff to help avoid inappropriate comments or actions
Help parents anticipate what normal grieving will be like
Provide straightforward information about cause of death if known. Use lay language.
Take time to sit down with parents when discussing information

nurses cope with this difficult topic before instituting new bereavement programs.[52] The Institute of Medicine's report, 'When Children Die' (2003) emphasizes that health professionals working with children and families should be trained to have basic competence in palliative, end-of-life and bereavement care as part of residency training, continuing education and model curricula.[5] On the basis of feedback from parents in this systematic review, it appears such models could benefit providers in obstetrics and perinatal care.

Any hospital which provides obstetrical or pediatric care should establish training and protocol for fetal or infant death. Not only should these include a concrete plan to help health care staff medically manage the demise, but there should be on-going training for staff on grief and bereavement issues and how to sensitively assist families experiencing these events. A number of national organizations have published recommendations for care in the event of perinatal death which may be useful for hospitals developing bereavement programs.[48–51]

Such a program should include interventions to help the family through the birth and death, guidance for providers on handling the deceased infant in a thoughtful and respectful manner and should emphasize that grieving parents will recall not only small acts of kindness but also insensitive comments, actions, or avoidance of the family for years or even a lifetime. Staff should also recognize that a patient's culture or religion may influence their decisions about medical interventions, care and handling of the infant at the time of death, autopsies, funerals and even

Table 2 Selected internet resources for providers

Gundersen Lutheran Bereavement Services
This program offers national bereavement training programs for healthcare providers who work with families experiencing perinatal loss. http://www.bereavementprograms.com
March of Dimes
Well-known for their work to prevent prematurity, birth defects, and infant mortality, the March of Dimes web site includes a collection of resources about pregnancy and newborn loss for families, friends, and providers. http://www.marchofdimes.com
Wisconsin Stillbirth Service Program
Part of the University of Wisconsin's Clinical Genetics Center, WiSSP provides education and support to families and care providers. The site includes a step-by-step Stillbirth Assessment Protocol for providers. http://www.marchofdimes.com

photographs. Finally, given the emotional challenges of caring for a family who have lost a baby, bereavement staff should anticipate the need for basic death and palliative care training for staff before implementing a perinatal program and the program should plan to have on-going training and education on this topic. Table 2 lists a few of the many internet sites with resources or training on perinatal death for health care providers.

As many families in this review cited inappropriate comments from hospital staff unaware of the death, any bereavement program should include a protocol to rapidly communicate news of the death. This information is important not only to those who interact with the patient and family during the hospital stay but also to outpatient providers who have and will care for the family in the near future. To share this information in a discrete manner during the hospital stay, many institutions post special symbols, pictures, or color-coded tags on the door to the patient's room (Figure 2); this allows all staff – from physicians to dietary staff to housekeepers – to be aware of the event and to act and respond in a thoughtful and appropriate manner.

Although a hospital bereavement program can incorporate a variety of interventions, few have been randomly or even systematically tested for efficacy. Many programs use techniques which are widely accepted as helpful but lack rigorous evaluation. Some may have unexpected or inadvertent effects on families. Future research in this area should focus on high-quality prospective observational or randomized, controlled trials of care for patients to determine how such interventions affect patient outcomes.

When a stillbirth or infant death is viewed as a traumatic event, it becomes clear that a random comment from a doctor or nurse at a time of high parental arousal may have far more impact than it otherwise might. In these settings, a provider's insensitivity could contribute to long-term difficulties in coping for distressed parents and might increase the chance of a complicated grief reaction. As

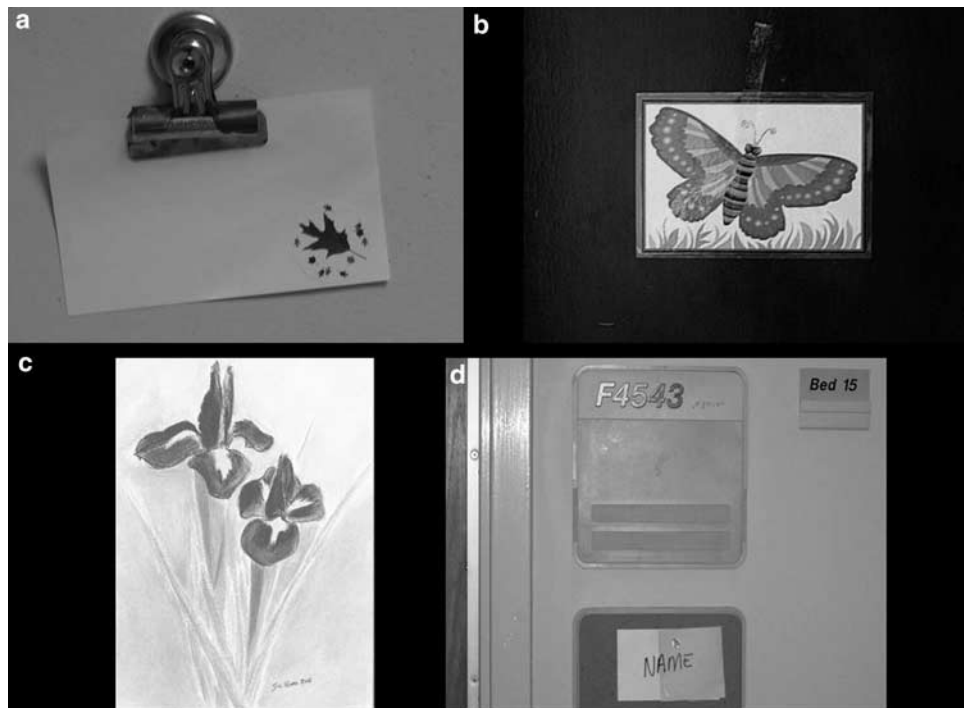

Figure 2 Symbols used to communicate perinatal death on hospital room doors. (**a**) Card with leaf print at the University of San Francisco Medical Center; (**b**) Butterfly at Barnes-Jewish Hospital in St Louis, MO; (**c**) Iris at Women and Infant's Hospital of Rhode Island in Providence, RI; (**d**) Bicolor name tag (yellow/green) at the University of Michigan Women's Hospital, Ann Arbor, MI, USA. Photos: Katherine Gold, MD.

seen countless times in this review, one thoughtless comment after a death may become engraved in a parent's memory even though the same comment in a routine setting might be distressing but have no permanent sequelae.

Like all studies, this paper must be viewed in the context of its limitations. The review was limited to experiences in American hospitals and required heavy reliance on qualitative studies, which offer rich information about experiences but which have disparate methods and do not allow for meta-synthesis of results or full application of MOOSE criteria.[14] The search process could potentially have missed important studies although a professional librarian was utilized to improve the quality of the search. Like all reviews, there is the potential of a positive publication bias, and subjects in these qualitative studies may at times reflect a biased sample of bereaved parents.

Perinatal care professionals must recognize the importance of their role at the time of fetal or infant death. Providers should be given increased education on how their behaviors may take on particular importance because of the traumatic nature of the loss and how small insensitivities can have profound impacts on bereaved families. Physicians and nurses should be comfortable discussing sensitive issues such as death and bereavement, and be trained to assist parents in navigating the grief process. Although no one can take away the fundamental grief of losing a baby, providers can potentially reduce the traumatic effects, which very frequently follow such a loss and improve the care of surviving family members.

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