

Original Article

How Bereaved Multiple-Birth Parents Cope with Hospitalization, Homecoming, Disposition for Deceased, and Attachment to Survivors

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OBJECTIVE:

To elicit bereaved multiple-birth parents' perceptions regarding support, disposition decisions, attachment to surviving multiples, discharge, and later coping.

STUDY DESIGN:

Narrative email survey of 70 bereaved parents with quantitative and qualitative analysis.

RESULTS:

Bereaved parents of multiples find neonatal hospitalization stressful. Not all caregivers acknowledged loss, although most parents would welcome brief loss discussions during survivors' hospitalization. Half of respondents felt social workers could help coordinate support or mental health care. Most participants recalled hospital support for loss, but only 43% recalled support for neonatal hospitalization. Respondents praised peer support and written materials. Parents felt ambivalent about disposition for deceased babies while comultiples were ill; most made prompt arrangements. Attachment to survivors was difficult for half. Breastfeeding and discharge planning were important, and 31% had difficulty coping at home.

CONCLUSIONS:

Caregivers must communicate better with bereaved multiple-birth parents, whose desires for support, loss discussions, disposition, and discharge vary considerably.

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INTRODUCTION

Perinatal caregivers increasingly confront the unique needs of parents whose multiple-birth children die. Between 1980 and 2002, the US live twin birth rate increased 65% to 31 per 1000, and the high-order multiple-birth rate in the same period increased over 400%, from 37 to 184 per 100,000 births.¹ Twins are five times, and high-order multiples 12 times, more likely to die in their first year than are singletons.¹ Moreover, a first trimester “vanished twin” occurs in 20 to 50% of multifetal pregnancies,² and later fetal loss happens in up to 5% of twin and 18% of triplet gestations.^{2,3}

Compared to parents of singletons, parents of multiples in neonatal intensive care units (NICUs) tend to have greater anxiety and attach differently to their children.^{4–6} Parents who conceive twins via assisted reproductive techniques report less prenatal anxiety, but greater parenting stress than those with spontaneously conceived multiples.^{7,8} Parents with disabled multiples may be depressed,⁹ and parents whose multiples die have a heightened risk of depression, prolonged or delayed grief.^{9,10} Some bereaved parents,^{11–13} but not all,⁴ have trouble attaching to surviving comultiples. A few loss scenarios are especially challenging, including multifetal pregnancy reduction, ongoing pregnancy after intrauterine demise of some fetuses, delayed interval delivery, and deaths of multiples born at borderline viability.^{10,13,14}

Few authors have solicited bereaved multiple-birth parents' recommendations for clinicians.^{10,11,15,16} Accordingly, the purpose of the present study was to survey a diverse group of such parents regarding their hospital experiences, support resources, disposition decisions for deceased children, attachment to survivors, and discharge concerns.

METHODS

Procedures

As previously described,¹⁶ invitations to complete the survey were circulated in late 1999, and again in 2001, through support groups for multiple birth, infertility, prematurity, and perinatal loss. These included a support organization for multiple-birth loss, email discussion lists, and online newsgroups (Usenet). To respect the anonymity possible with email, respondents were not queried about demographic variables. Three people who separately contacted the author about bereavement were also recruited. Volunteers were asked to complete an email survey regarding their experiences, and

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Conflicts: Current or former member of several networks and organizations surveyed. No income derived from any institutions, networks or organizations mentioned.

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were informed of the author's intent to publish study findings. In the survey's introduction, participants were advised that disturbing emotions and memories could be triggered by the topics, and that they were under no pressure to reply. Return of a completed survey indicated consent.

The author did not submit this survey for institutional review board approval prior to distribution, viewing it as a public health surveillance activity to assess trends from a broad geographic distribution of parents who had suffered a multiple-birth loss. Participant anonymity was preserved, and the data were analyzed separately from identifiers. Risk was considered minimal for an Internet survey of parents using support groups.

Subjects

In all, 71 surveys were submitted, one from each couple. Demographic characteristics voluntarily disclosed by participants are summarized in Table 1. Births occurred between the late 1980s and 2001. Parental age at delivery ranged from early 20s through early 40s, and both spontaneous and assisted conceptions are represented. Most participants were married and female, with two single and four male respondents. All were apparently North American, with many locales represented. Respondents reported Christian, Jewish, Islamic, or no religious faith. A total of 11 parents reported health-care occupations, and several had written books, essays, or websites about their losses.

Reported causes of respondents' losses included anomalies, multifetal reduction, intrauterine demise, twin-to-twin transfusion syndrome, complications of monoamniotic twinning, placental problems, adverse intrapartum events, delayed interval delivery, postoperative complications, and the effects of prematurity. Many parents endured more than one loss from their multiple pregnancies, and four had a preceding or subsequent singleton

loss. Moreover, two respondents had losses in two separate pregnancies, but only one discussed both losses.

Data Collection and Analysis

All surveys were completed and returned by email, except for one completed by telephone at the participant's request. A bereaved singleton parent's responses were excluded. Relevant information was extracted from additional materials some participants had written about their loss. Two participants requested referencing of their published works, with the understanding that this compromised their anonymity.

Categorical responses (Yes–No–Not applicable/Not answered, or Positive–Negative) were tabulated manually. For qualitative responses, distinct ideas were entered into a Microsoft Excel spreadsheet, and a modification of Eaves' grounded theory approach¹⁷ was then used to group ideas into lower- and higher-level themes. Major themes are summarized in the Results, and the Discussion relates findings to previous literature and offers suggestions for clinicians.

The author reviewed original responses after completing the spreadsheet to verify correct transcription of each participant's intent. After manuscript preparation, the author attempted to contact all respondents to review the interpretation of their comments. In all, 23 could be reached, and one submitted brief corrections.

RESULTS

After a discussion of concerns that parents expressed with different types of losses, quantitative results from Table 2 are integrated with qualitative results. In summary, caregivers did not always communicate with each other or with parents about loss; when they did, most interactions were positive. Social workers and hospitals can provide valuable support. However, some troubling interactions occurred between parents and staff, and parents faced major challenges with disposition decisions, attachment to living multiples, breastfeeding, discharge, and daily responsibilities.

Concerns and Emotions Associated with Prenatal and Neonatal Loss

A mother who lost some fetuses during pregnancy and carried remaining multiples to later delivery remarked: "Babies who die are beautiful human beings, no matter how far in pregnancy they died.". Such parents were not always well informed about whether fetal remains would be identifiable when survivors were born. One woman said about her second-trimester demise, "I feel robbed The OB said there'd be nothing left. The pathologist could see fingers and toes, he was a boy." Another woman asked at delivery about fetuses that had spontaneously aborted. "The OB ... told me there was nothing left. From what I've read ... , there is something to see. At 13–14 weeks, my babies were moving."

Table 1 Self-Reported Characteristics of Survey Respondents (*N* = 70)

Characteristic	Number (%)
Female	66 (94.3)
Married at time of multiples' birth	68 (97.1)
Employed in health-care industry	11 (15.7)
Prenatal loss	24 (34.3)
Postnatal loss	50 (71.4)
Intrapartum loss	2 (2.9)
Initial fetal number = 2	53 (75.7)
Initial fetal number > 2	18 (25.7)
No survivors	17 (24.3)
1 survivor	48 (68.6)
2 survivors	6 (8.6)
Prior or subsequent singleton loss	4 (5.7)
Loss in two multiple pregnancies	2 (2.9)

Table 2 Participant Recollections, Choices, and Opinions (*N* = 70 Except Where Noted)*

Theme	Yes Number (%)	No Number (%)	Not applicable/not answered Number (%)	Other
NICU staff remembered or acknowledged loss	34 (48.6)	25 (35.7)	11 (15.7)	
Caregivers should discuss grief in NICU	33.5 (47.9)	17.5 (25)	17 (24.3)	Let parents choose 2 (2.9)
Social worker should help with social network & mental health	33 (47.1)	9 (12.9)	26 (37.1)	Unsure 2 (2.9)
Support given for bereavement	53.5 (76.4)	13.5 (19.3)	3 (4.3)	
Support given for NICU stay	30 (42.9)	17 (24.3)	23 (32.9)	
Prompt burial/cremation chosen (<i>N</i> = 71)	39.5 (55.6)	10.5 (14.8)	16 (22.5)	Should offer burial/baptism for reduction 2 (2.8) Hospital disposition done with consent 1 (1.4) Hospital disposition done without consent 3 (4.2)
Trouble attaching to survivor(s) (<i>N</i> = 71)	24.5 (35.0)	28.5 (40.7)	18 (25.7)	
Trouble planning discharge & coping afterward	22 (31.4)	14 (20.0)	34 (48.6)	

*Where *N* = 71, each loss was counted separately for the couple who described two multiple-birth losses. Mixed positive and negative responses for other participants were counted as 0.5 Yes, 0.5 No.

Conversely, a mother who had multifetal reduction was unprepared at birth when her obstetrician offered to show her the reduced fetuses.

Women who elected multifetal reduction wanted more information about the procedure’s medical and emotional consequences. Two speculated about the reduced fetuses’ genders, and one wishes she had been told she could name or acknowledge them. One asserted, “Reduction is a sensitive subject. Until you walk a mile in my shoes, don’t judge. That is for God ... alone.” A second related, “this was a sacrifice that had to be made to save some of the babies, but I ... wished I could take some out and save them for later.” A third confided, “I believe reduction saved one of my children. It’s the not knowing that kills me.” A mother who spontaneously lost some high-order fetuses would have had to reduce otherwise. “If I tried to carry all of the babies, I would most definitely lose them all. ... I also look at my survivor knowing she probably would have been ... chosen for reduction. This also wracks me with guilt.”

Other women underwent delayed interval delivery (premature birth of one child, with attempt to delay delivery of the remaining children) and felt empty, with one wondering if the remaining baby missed his/her sibling. “When one died, a part of me died, too. I was no longer a mother getting ready to raise twins.” A woman hospitalized between the births recalled, “It was hard to remember why I was doing it. I didn’t feel or look very pregnant anymore. If I would start thinking about the baby still alive inside me, I would tell myself to stop because I didn’t want to bond with this baby that I thought I would lose too.”

After a neonatal death, parents felt strong emotions when they returned to NICU to see survivors. They appreciated staff who acknowledged their pain. “It was pretty strange ... to go into NICU and have only one bedside to sit at.” One mother felt like screaming, “My baby just died, I have to come back to this hell-hole... I am going to blow.” Another showered and “put on makeup for my Academy Award performance! The last thing a grieving mother wants to do is face the public. I wanted to stay in my room...but marched in there and was glad I did because nothing ... made me happier than ... my surviving baby.” A mother of high-order multiples recalled, “For two days I would not go back.... I did not want to bond any more with babies that could still die....And then...I ... realized I was the ONLY advocate that [they] had.”

Given their troubled emotions, parents did not want to hear about intact sets of multiples. One mother wanted her surviving twin to be nipping after surgery, but “the nurses said it was so crazy because of a quadruplet birth they didn’t know when they’d get to it.” A sole survivor was surrounded by intact sets of twins, whose family members “trample[d] in to see the twins, triplets, etc. and gush over the babies. I would just turn my back and cry to myself,” reported the grieving mother. Comments from other families could be painful, as when a mother of twins told the mother of a lone triplet, “You wouldn’t know how hard it is to carry two.” The grandmother of other twins commented about her daughter-in-law’s “handful” and envied a bereaved mother for having just one baby — the last of high-order multiples. The bereaved mother told her “... as politely as I

could that my daughter is a survivor and she never said anything more to me.”

Staff Failure to Communicate with Each Other and Parents about Loss

Considering that NICU may be “an integral part of grieving [for] one and hoping for the other,” it is disturbing that one-third of respondents felt that not all caregivers knew about, or acknowledged, losses, sometimes despite bereavement markers or an isolette labeled “Twin B” (Table 2). No marker was posted when one mother was readmitted for postpartum complications, although both twins had died days after birth. Thus, a medical student asked how her “baby” was, whereupon she replied, “They died” and broke down (Howser¹⁸ p. 33). A nurse told a second mother when a new preemie was placed next to her survivor, “Look, they could be twins!” The mother, overcome by emotion, left and cried for hours. A third mother received an unwanted NICU graduate newsletter for 6 months, despite repeated calls to report that her son had not graduated — he’d died.

Positive Experiences with Hospital Staff after Loss

Parents appreciated caregivers who used the deceased children’s names. Tears from clinicians were considered “extremely appropriate.” Some skillfully focused on the living baby without forgetting others who had died. A social worker helped one couple recognize potentially bothersome events, such as going home with only one child. Some parents found comfort in hearing about other losses. Several were moved when caregivers asked about and attended funerals. One hospital’s policy was for obstetricians and neonatologists to write condolence letters, and a nurse at another institution addressed a letter to a surviving twin, describing her memories of the girl’s deceased sister.

Many stressed parents of survivors in NICU did not want constant reminders or inquiries about grief (Table 2). One “did not even begin to grieve until my surviving babies were home and I realized I should have had four.” Many just tried to “hold it together.” One summarized, “No matter how OK parents with a NICU survivor look, their life is out of control. They may want to be the ones to bring up the loss.” Parents appreciated hearing “I’m sorry” around the time of death, and simple inquiries, such as “How are you guys doing?” Although some parents “had to bury grief in a shoebox under the bed,” others needed to talk. Clearly, those who asked about their baby’s delivery, death, medical care, or appearance wanted answers and support. Wrote one mother: “Even their birth is a blank. How did the boys lie? Did they cry? How did they look? What did my doctor think when he pulled them out? ... What was said? Who cut their cords? Who cleaned them and who rushed them to intensive care? ... I have nothing of my boys and need to know every minute of their little bit of life” (Fifield,¹⁹ p. 56).

Isolette labeling and placement were important, but parent preferences differed. For example, one parent was happy her survivor’s incubator said “Twin A,” but another said the “biggest kick in the butt” was the “Twin A” label. One family was stunned to have Twin A transported to the same tertiary hospital isolette where Twin B had died earlier.

Parent Views of the Social Worker’s Role and Mental Health-Care Needs

Nearly half of respondents believed that parents would value caseworkers that offered to coordinate their support network (Table 2). One respondent said this should “absolutely” be offered, after discussion with parents. However, others felt that a social worker’s intervention could meddle with an already chaotic life. Some parents did not want strangers involved, or said the caseworker’s personality would determine whether they accepted help. “What the social worker can and should offer is support in linking up with therapy/counselors/chaplains/overnight accommodations, as well as practical help with insurance, finances, unemployment, etc.,” summarized one parent. A caseworker must understand the family’s support system, including marital or extended-family conflicts.

To minimize parents’ repetition of their story, a social worker could telephone family, friends, or the funeral home to report a death. To maximize parents’ time with their children, caseworkers could ask one relative or friend to coordinate rides, meals, or child care. One parent observed, “Sometimes it is easier to get strangers to help. You can’t really tell a family member no thanks ... without upsetting them.” One proposed low-cost hospital daycare for siblings, while another recommended that hospitals introduce parents whose babies have cerebral palsy or other disabilities to parents who are raising children with those special needs (Fifield,¹⁹ p. 92). Lastly, if multiple-birth siblings are hospitalized at two or more medical centers, all caseworkers should communicate regularly with each other.

Finally, four respondents wanted mental health consultation, with one noting ironically that her hospital’s grief counselor was on maternity leave. A bereaved health care worker was “appalled at the [hospital’s] lack of psychosocial intervention.” Serious depression was sometimes undetected. One mother could have used both pre- and postnatal psychiatric assistance. “I think they should have at least one staff member trained ... to comfort parents ... through things like this. ... I needed to vent and there was no one around. ...” Some parents tried several counselors before they were satisfied. “Therapy was a great help, but it has to be with the right person, at the right time” (Fifield,¹⁹ p. 70).

Support Resources Offered by Hospitals

In terms of organized support, three-fourths of respondents recalled receiving loss support resources from hospital staff, but only 43% of all respondents remembered getting support for the NICU

experience. The hospitals offered leaflets, books, and referrals to similarly affected parents or support organizations. As detailed in Table 3, many parents considered these resources beneficial, especially when tailored to their unique type of loss. Several appreciated staff members who shared personal experiences of loss or premature birth. Informal support from family, friends, hospital workers, and clergy helped, as did personal strategies such as humor, hope, or compartmentalizing grief. However, other parents did not benefit, or chose to cope alone. A few parents felt they received too much printed matter. A total of 11 parents did not attend support groups, citing worry about their survivor's condition, or discomfort at the uniqueness of having lost two children or of having a loss with survivors. Two couples felt they attended support groups too soon, with one losing their survivor after attending a group for parents of surviving multiples.

Negative Experiences with Hospital Staff after Loss

Despite many positive experiences, some parents were distressed by staff members' responses to death. Clinicians crowded one mother, encouraging her to touch her dying child. Conversely, when another couple's twins were born before viability, the nursing supervisor ordered ice and a biohazard container. Although the caring primary nurse softened the mandate by placing them near

an air conditioner with a pillow and blankets in a box, the mother felt that her babies were like dead kittens. Another nurse was uncomfortable when a couple's child deteriorated, and ushered them out, urging the parents to let their son rest; he died that night. A physician told this mother she had to free her son's spirit to "go to the light." She felt this placed guilt on her, denied permission to grieve, and implied that her son would wander in limbo if she failed. Other nurses avoided families whose babies were dead or dying, but a compassionate substitute nurse made an accustomed caregiver's absence bearable.

Caregiver comments could be hurtful. A brusque nurse told one mother, "You're young enough to have other multiples" (Fifield,¹⁹ p. 62). A "worse than useless" social worker said to other parents, "I think full-term parents [in NICU] have it worse than preemie parents because they expected a healthy child," and "Parents who lose one child have it worse than parents who lose a multiple." One mother wrote, "If I heard the term 'wimpy white boy' one more time, I would lose my mind.... We viewed him as a little baby boy who fought hard to live." The term "miracle baby" for the survivor conveyed to one parent the impression that the deceased child was less than miraculous (Fifield,¹⁹ p. 83). Another asserted that staff must not trivialize a loss by saying "Just be glad your survivor's alive."

Disposition Decisions and Memorial Rituals

Parents found final arrangements for deceased babies to be difficult, and a few felt they received no guidance. In eight cases, the husband or other relatives made plans without the mother; friends or hospital staff helped other couples. A hospitalized mother felt uncomfortable discussing funeral plans next to roommates with complex pregnancies.

Parents were often grateful to have memorials, since "there will never be a first day of school, birthday parties, graduation, or a wedding." One mother "wanted the world to know we had a son and he was a part of our life & his sister." One family held a naming ceremony for a reduced fetus, and two scattered ashes of their deceased multiples 6 or 12 months after the children's birth.

When parents had survivors, ambivalence about scheduling disposition was common. Parents felt "hopeful, yet expected to be empty-handed." Two couples wanted to wait, but felt that would be like "planning the survivor's death." Thus, nearly 80% in this situation opted for prompt final arrangements (Table 2), sometimes for "semi-closure" so they could focus on survivors. One mother remained with their survivor while the father videotaped the dead twin's graveside service. Another observed, "At times of death people tend to be spiritual if not religious, so I wanted her to be buried [promptly] according to [our] traditions as close as possible." Three couples reserved adjacent funeral plots in case survivors died.

One in five preferred delayed services. One couple explained, "Our beliefs are that we hold a memorial to celebrate the life on

Table 3 Support Resources Used and Desired by Bereaved Multiple-Birth Parents (N = 70)

Resources perceived as helpful	Number (%)
Center for Loss in Multiple Birth	18 (25.3)
Written material on loss or NICU hospitalization	15 (21.1)
Contact with bereaved multiple parent	5 (7.0)
Multiple birth organization or club	5 (7.0)
Infant loss or NICU support group	5 (7.0)
Other contact with NICU parents	5 (7.0)
Trained NICU volunteer parents	4 (5.6)
Staff member who had had a loss	4 (5.6)
Internet support	3 (4.2)
Annual remembrance day	1 (1.4)
Resources desired, but not offered	Number (%)
Mental health consultation (psychiatric or counselor/social worker)	4 (5.6)
Parent peer contact	4 (5.6)
NICU, grief or loss info	3 (4.2)
NICU group more than monthly	2 (2.8)
Reduction support	2 (2.8)
Trained NICU parent facilitator	2 (2.8)
Grief counselor	1 (1.4)
More flexible visiting hours, not requiring parent presence for other visitors to come	1 (1.4)

earth and the passing of the soul into life with God. Funerals simply lay an empty shell to rest. We could not celebrate until we knew if [our son] was going to survive.” Other couples couldn’t have endured two or more separate services. One couple waited for their daughter’s burial and brought her living twin, who cried inconsolably.

When parents lost all of their multiples, four couples found it meaningful to bury them together, and two couples whose children died at different times kept ashes in the same urn. A considerate funeral home director did not seal a casket after some multiples died, and was able to add the last child who died soon after.

Some parents with multifetal reduction or spontaneous fetal demise urged that hospital staff suggest burial or cremation, rather than hospital disposition. A mother whose deceased fetus’s body was sent to the pathology lab lamented, “I wish so badly that I could have had [a funeral] for him.” One hospital would not allow a mother awaiting delayed interval delivery to bring a casket into the hospital chapel, although another hospital arranged for a mother to attend her baby’s funeral while on magnesium sulfate.

Challenges in Attaching to Surviving Multiples

Following loss, roughly half of respondents with survivors believed they had difficulties attaching to them (Table 2). Their reasons included stress, logistical difficulties, parental illness, family emergencies, survivor irritability, and feelings of unreality, shock, and powerlessness. A medically trained parent stated, “It isn’t easy ... seeing your child hooked up to all those wires and tubes ... I sat and cried all day long.” Many expressed ambivalence.

“Bittersweet is such a true statement. I remember holding [our surviving son] and getting our picture taken and feeling guilty that I was actually smiling,” said one mother. Another wrote, “There was a measure of disassociation that I felt in addition to the intense love I was prepared for him to die at any time.”

After the sorrow of loss, some parents actively resisted attachment to remaining fetuses during ongoing pregnancy, or to surviving neonates after delivery. One mother did not dare to hope until her son came off the ventilator, while a second respondent finally realized her baby was truly hers during respiratory bagging. A third parent waited until the last moment to prepare the baby’s nursery, while a fourth did not feel her child was really hers until after homecoming.

Another factor that complicated attachment for a few parents was a living child’s resemblance to dead siblings. One mother “saw” her deceased triplet every time she looked at her survivors of opposite gender. A mother who lost an identical twin commented, “It was very disturbing to have left a dead baby at the hospital with his image in death etched on my mind, and to have a baby at home with the identical face.”

Some parents felt enhanced appreciation for life after suffering loss: “[We are] so thankful we have him in our lives,” and “She is the joy of our lives, even more special.” Accentuated attachment

was apparent at times, e.g., “I may have overbonded,” and “I needed to bond for my own sanity.” Physical contact was quite important to some parents, who felt devastated when holding their children was impossible or restricted.

Breastfeeding

“Better help is generally needed with breastfeeding,” said one parent. Postpartum nurses refused to help one mother pump milk for a survivor, and two mothers struggled alone for weeks to breastfeed. Another received mixed messages; some nurses said she could unwrap her child to breastfeed, but others worried that exposure would destabilize the baby’s temperature. Parents valued lactation consultants, who needed to be informed about loss. One consultant did not know a baby was a surviving twin, and skipped a pamphlet section about breastfeeding multiples, saying “I guess you don’t have to worry about that.” The mother wept as the father explained their loss. One mother noted that emotions interfered with milk production, while unique pain was articulated by another who wrote about the dual breast pump, “I hated everything that came in twos” (Fifield,¹⁹ p. 73).

Discharge Planning for Survivors

Homecoming brings logistical, mental, and emotional challenges for bereaved parents with survivors. One mother commented, “I really don’t think anyone could fully prepare me for what it would be like when they came home.” Some parents were acutely aware they were not bringing all of their children home. One cried all day, while a second felt, “I didn’t fail them both if he could make it home.” A third mother would have liked to review a checklist several days before discharge, since she was too excited on the actual homecoming day to pay attention to information she was given. Whereas many parents praised NICUs for steadily increasing parental involvement in care and for thoroughly planning home services, four couples received less than a day’s notice before discharge. Reported one mother: “Bringing home a baby on all that equipment was terrifying. Things were pushed along quickly and I had to ... slow everyone down and make sure I knew everything.” Despite her training, a health-care worker felt she was still a first-time mother and didn’t know how she’d cope with monitors, tube feeding, and oxygen. She called for better support in helping parents’ transition to home.

Coping after Discharge

Roughly one in three parents reported difficulty coping at home (Table 2), with some experiencing depression or prolonged fear for survivors. “Everyone is willing to help out the first few weeks but then support dwindles.... When you finally come home, everyone thinks your stress is over, but you’re now home with a ‘newborn’ acting baby.” Parents managing two or more survivors were sometimes overwhelmed, and one felt guilty about attaching differently to each child. Three mothers felt a visiting nurse helped

more for emotional than for practical needs, and one with a special-needs survivor said a religiously affiliated visiting mother program “saved my life.”

Some employed parents noted difficulty concentrating or emotional breakdowns at work. Colleagues and supervisors were not always supportive. Functioning was especially problematic for bereaved health care workers. Three grieving hospital workers whose duties brought them to NICU confronted painful, heartbreaking memories of horrific days. One reported, “It is hard to work with multiple-birth moms, moms with losses, substance abuse moms, questions about how many children I have, etc.” Another recommended that a counselor be available to discuss possible stresses of returning to work after perinatal loss. “As hospital employees we will encounter situations that remind us of our children. It is like that with all heartbreaking endings . . . , whether it is a parent, spouse, family member or child or even a friend that dies. I really thought I could go to the NICU without any problems. Had I been told, I might not have tried to be so brave.”

DISCUSSION

Although formal institutional review board (IRB) approval was not sought prior to this survey, some online surveys have been deemed exempt from IRB review.²⁰ Survey risks are usually minimal, this study’s participants were drawn from organized sources of support, and the protocol for confidentiality, consent, and debriefing of participants met criteria described in several references.^{20–23}

Caution is advised in interpreting quantitative findings, due to many sources of bias. Although a recent study found diversity in self-selected online survey samples, with results comparable to traditional surveys,²⁴ sampling bias is inevitable in a voluntary Internet survey of support group users.²² Health-care workers and experienced writers are over-represented in this study, and Internet group users may be better educated and wealthier than average, although the opposite has also been observed.^{25,26} Furthermore, online support group users may be more depressed than those in face-to-face support settings,²⁷ and introverts may become more isolated through Internet use.²⁸ Recall bias is probable,²³ since some births occurred more than ten years prior to the survey. Despite these caveats, themes in this study closely resemble those of more representative samples.^{11,12,15,29}

Strengths of the study include details on diverse coping strategies used by parents, and practical suggestions for caregiver response. Participants were a heterogeneous group, expressing contradictory preferences. Since bereaved multiple-birth parents do not have uniform desires for assistance, each parent’s preferences must be elicited without preconceptions. Grief for multiple-birth losses is complex,^{12,15,30} and sometimes is suppressed or delayed.¹³ Although grief intensity is the same for loss of a singleton and loss of one twin,^{10,11,15,30} one-fourth of

parents facing crises with surviving multiples did not want long discussions of grief.

The types of hospital and social support valued by participants match other studies’ findings.^{15,29} Support specific for their situation was most appreciated. Swanson et al.¹⁵ found that strong social support correlated with better adjustment to loss, and lack of understanding from inexperienced social workers was very unhelpful. Condolence letters from clinicians may be cherished when they includes details about the patients’ hospital stay.³¹ Caregivers often knew the deceased children best, and they can help parents reconstruct the story of their child’s brief life (Fifield,¹⁹ p. 56).^{32,33} Bereaved parents of multiples may appreciate matching mementos or photos of multiples together.^{10,16}

Two major disposition dilemmas arise. With early multiple-birth loss, parents and clinicians must know that fetal remains may be identifiable at term after a 12-to-14-week demise.¹⁰ With neonatal loss when survivors are critically ill, most parents made prompt arrangements for deceased children, although they often needed help with choices. Some parents felt that prompt disposition enabled them to concentrate better on survivors, although a delay allows children to be placed together if comultiples die later.

The difficulties that bereaved parents in this study experienced in attaching to their living children, and in early parenting, resemble findings with other parents of preemies.³³ Several parents reported that their guarded attitude yielded in a few days to a feeling of attachment and advocacy for their survivors, as noted by Netzer and Arad.¹² Staff can gently encourage apprehensive parents to interact with survivors, but must not minimize the impact of their loss.^{11,15} Sentiments noted by this study’s multifetal reduction patients echo earlier descriptions,^{14,34–37} and caregivers must also respect parents’ confidentiality after iatrogenic loss. Anxiety before the survivors’ birth; fear for the survivors’ death, disability or loneliness; and difficulty attaching to a gravely ill survivor, or to either the anomalous or the healthy twin of a discordant set, have been noted.^{11,12,15,38,39}

Disclosure of loss to other parents in a NICU, with bereaved parents’ permission, may prevent embarrassing incidents. NICU staff can ask parents how to label surviving children’s isolettes, e.g. “Triplet A” vs the baby’s name, and they can place survivors away from intact sets of multiples or the location where a sibling died.¹⁰ Bereaved breastfeeding mothers desire greater assistance, respect for their choice, and awareness of loss effects on lactation.⁴⁰ Finally, caregivers must note the lasting negative impact of bereavement and prematurity on some parents’ work and parenting performance.^{12,14,33,41}

SIGNIFICANCE

Clinicians may find it hard to confront intense emotions and dilemmas with bereaved multiple-birth parents, and Cuisinier et al.¹¹

found that parents often felt they should not openly discuss their feelings. Fifield's comment about the general public applies equally to professionals. "It's one of the paradoxes of grief that when people try to solve it they cause resentment, whereas if they accept the sadness and aren't afraid to enter into it with the person who is mourning, they lighten the isolation, both the mourner's and their own" (Fifield,¹⁹ p. 87). It is crucial for caregivers to communicate well with each other and with parents, mindful that not all parents desire the same kinds of support. Caregivers can present a variety of options for support, mementos, disposition, breastfeeding, and discharge planning, so that parents can choose what meets their needs. All bereaved parents can be reassured about the normalcy of ambivalence, feelings of guilt or failure, attachment challenges, anxiety for survivors, and delayed grief.^{10,14}

Although parents often find comfort in their surviving multiples,^{10,11,15} disposition decisions and emotions in NICU after loss may be painful. The difficulties that bereaved multiple-birth parents describe in attaching to survivors resemble those reported for intact sets of multiples and premature singletons.^{4-8,11-13,15,33,38,39} Severe depression may persist for years.^{8,10} Mental health services, visiting nurses, and community organizations may help distressed parents, and employers can offer counseling to bereaved workers before they resume their duties. Future research could prospectively evaluate the perceived value of specific bereavement interventions for parents of multiples, or parental attachment to surviving multiples.

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