Beneficial Effects of a Hospital Bereavement Intervention Program after Traumatic Childhood Death

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Purpose: An investigation of the experiences of parents grieving the traumatic death of their child, the initiatives that helped, and common parental concerns that would benefit from improved education.

Methods: From January 1, 1995, to December 31, 1998, 81 of 3,501 children admitted to our pediatric trauma center died. An attempt was made to enroll all parents. Interactions included family contact at hospital, home/funeral home visit within 1 month of death, educational meeting with parents and 15 supporters at a restaurant within 2 months of death, follow-up survey to parents/supporters, and final interview/ survey with parents in 1999–2000.

Results: Seventy-seven families were enrolled; 59 families completed the educational meeting with supporters, and 245 parental supporters returned surveys. Supporters were likely to use proposed interventions (82%), were more accepting of the duration of grief (94%), and interacted with parents more often after the death (78%). Parents (n = 44) felt the hospital staff was appropriately sensitive to their child (90%), themselves (93%) and prepared them for their child's death (81%). Parents (n = 54) on behalf of 37 children have completed the final interview. Poor conceptualization of aspects of the medical care and brain death, and delayed regret for missing the opportunity to donate organs, were recurring themes.

Conclusion: We conclude that parents' unanswered questions or misconceptions regarding brain death, organ donation, and their child's medical care adversely affect their grief; that "normal life" for parents is challenged as they struggle to establish a new sense of normal; and that hospital and trauma service personnel can positively impact the grieving process with appropriate training.

Key Words: Trauma, Pediatric death, Ethics, Medical, Bereavement, Organ donation, Brain death.

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ollowing an in-hospital traumatic death, delivery of the "bad news" is customarily delegated to a physician.¹ How the news is delivered will have a lasting effect on family and friends and may affect their ability to come to terms with the death.^{2,3} There is a growing body of evidence suggesting that bereaved persons whose grief and pain are not addressed may become "secondary victims," as they are more at-risk for a variety of problems such as severe mental disorders, alcohol abuse, and violence.⁴

During the course of training, medical students and residents receive little formal education in compassionate care. In a previous study evaluating the grieving process of parents after the traumatic death of a child, we developed some guidelines for compassionate communication with parents.⁵ We also found that many parents continued to grieve for months and years after the death, and lived essentially without hope. These parents felt

that "feeling good" would be a betrayal of their child and would indicate that they had forgotten that child. "Feeling bad" is a parent's way of keeping their child alive, although it proves to be a very painful and ultimately destructive way of remembering.

The program that will be discussed is a sequel to our prior program. Although a primary goal was to develop a hospital-based pastoral care program for parents bereaved by the traumatic death of their children, for the purposes of this study our aim was to determine initiatives that helped parents grieve and common parental concerns that would benefit from improved education of both providers and parents.

PATIENTS AND METHODS

From January 1, 1995, to December 31, 1998, 81 of 3,501 children admitted to our pediatric trauma center died. Kosair Children's Hospital in Louisville, Kentucky, is a 227bed facility that serves as the regional trauma center for pediatrics. An attempt was made to involve all parents prospectively.

The Bereavement Intervention Program (BIP) is organized around four chaplain-parent interactions, which will subsequently be described: family contact at the hospital, home/funeral home visit within 1 month after the death, educational meeting with parents and 15 supporters at a restaurant within 2 months of death, and in-home interview/ survey with parents at 12 months or later after the death.

Hospitalization

Per hospital protocol, a chaplain is called for every death.⁶ Chaplains assist in comforting parents, extended fam-

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ily, friends, and hospital staff at the time of death. Parents are offered time alone with the body, and are counseled on involvement of surviving children. If the death occurs in the emergency department, there is a separate mourning room available for parents and their supporters. Whenever possible, representatives of the family faith tradition are contacted and asked to assist the family. Appropriate religious rituals are offered. Actual BIP activities begin at the time of death. Parents receive a brochure entitled, *What Next?* It provides instructions for contacting the funeral home, securing information about the autopsy, coroner, and organ donation; and it provides a brief description of how to tell surviving children of the death. Names and telephone numbers of support groups are provided. A video, *A Child's View of Grief,* is provided if there are surviving children in the home.

First Home Visit

Ideally, the first home visit occurs at the funeral home during "visitation" and lasts no more than 15 minutes. The chaplain expresses condolences and describes the home meeting that will follow in approximately 2 months. The chaplain also solicits questions parents have about their child's accident or treatment. If questions arise, the chaplain researches a response and responds to the family in a timely manner.

Educational Event

This third initiative is the centerpiece of the BIP. The chaplain contacts the parents and together they select a restaurant with a private dining room that is convenient for the family. The chaplain encourages parents to invite 15 of their supporters (e.g., family, friends, co-workers, church members) to the restaurant for a meal (paid for by grant funding) and a 1-hour program led by the chaplain. Three assumptions form the basis for the educational component of the BIP: parents can be best helped by the people they spend time with every day, the supporters who agree to attend the meeting are likely to be highly motivated to learn how they can help because they have a stake in the parents' grief process, and supportive care can be substantively enhanced if a number of myths about the nature of grief (e.g., the worst grief occurs early on, time heals all wounds) are dispelled. After the meal, the chaplain uses slides and an interactive lecture format to describe four needs of bereaved parents:

- 1. Parents need supporters to remember their child. Specifically, parents want supporters to talk about the child, tell stories, remember birthdays and anniversaries, and so on.
- 2. Parents need supporters to appreciate the significance of their grief. Because supporters understand the profundity of the pain, they are more empathetic toward parents and will be more tolerant of the time parents will require to work through the experience.
- 3. Parents need a multifaceted, initiative-taking support network. Each facet of the parents' social world brings

its unique perspective and helping gifts. Supporters must own the initiative to care for the parents.

4. Parents need supporters to "hang in there" with them. Parental grief is more like a marathon than a sprint. Long after supporters have worked through the emotional upheaval caused by the child's death, parents will still have a lot of work to do.

Two weeks after this meeting, a Likert scaled evaluation is sent to parents and supporters. The parents' survey measures whether the frequency of supporters' caring behavior changed since the meeting. The Likert scaled evaluation sent to supporters asks them to evaluate changes in their caring behavior toward the parents. The data from parents and supporters was combined into respective data pools.

Final BIP Initiative

This initiative commenced in the summer of 1999. A chaplain attempted to contact a parent of each of the 77 children enrolled in the BIP to arrange an in-home or phone interview. Because the interview becomes a part of the parent's bereavement course, the chaplain made whatever adjustments were required in the interview to ensure that the experience was meaningful for the parents. A 93-question interview guide used both Likert and open-ended questions to survey a wide range of topics. This was a qualitative assessment designed to explore and describe the personal and social phenomena of childhood death from the parents' perspective. Parents were asked about communication in the hospital, interactions with the coroner, organ procurement organization representative, chaplain, pediatrician, clergy, and religious community. Parents were asked about their religious behaviors, hope, psychiatric history, bereavement activities, job history, self-reported adjustment, and family relationships. Specific questions addressed the nature of the care provided by supporters. The correlation between the mothers' and fathers' responses to select questions including the significance of the support network, organ donation, and religion were subjected to a paired groups t test with significance detected at the p < 0.05 level.

RESULTS

Seventy-seven families were enrolled; 59 families completed the educational meeting with supporters, and 245 parental supporters returned surveys. A compilation of survey responses from parents and supporters is summarized in Tables 1 and 2.

Parents (n = 54) on behalf of 37 children have completed a final interview. The mechanisms of injury causing the deaths are listed in Table 3. Of the interviews, 26 were performed in person and 11 by phone. There were 4 families who refused the final interview, 22 families that could not be located after the death, and 14 families that did not respond to phone messages or said they would return a call and did not. A few of the families who participated in the final interview did not complete all

Table 1 Parent Survey after Educational Meeting(44 Individual Responses)

Survey Items	Responses (%)
Time in hospital	
Staff prepared you for death	81
Staff sensitive to child	90
Staff sensitive to you	93
Treatment understandable	90
Chaplain's first visit	
Parents wanted a meeting	80
Chaplain meeting helpful	90
Meeting answered questions re: care	78
Meeting with supporters	
Supporters remember child	91
Supporters accept adjustment time	89
Supporters call, visit, take out and write more	73

Table 2 Supporters Survey after Educational Meeting(245 Individual Responses)

Survey Items	Response (%)
Helped you understand parents' journey	95
Prepared you to care	82
Likely to use advice	82
Taken specific actions to remember the child	69
Accepted parental adjustment time	94
Call, visit, take out, or write more	78

Table 3 Mechanism of Injury Responsible for Death

Mechanism of Injury	No. of Deaths
Passenger in vehicular crash	14
Pedestrian struck	10
Penetrating injury	5
Fall	3
Burns/smoke inhalation	2
Equestrian injury	1
Drowning	1
Crush injury	1

Table 4 How Are Parents Doing?

8	-
Response	No. (%)
Terrible	2 (4)
As well as expected	17 (31)
Okay	13 (24)
Good	19 (35)
Other	3 (6)

portions of the interview, which accounts for some variation in total number of responses to individual questions.

At the final interview, parents were asked the question "Generally, how are you doing?" Table 4 lists the replies. The following are examples of the self-reported definitions that match the behavioral terms. "Terrible" describes a parent who might have suicidal ideation, appetite and sleep disor-

ders, and continues to be preoccupied with the death of the child. "As well as can be expected" describes parents who have some sense of their own improvement but tend to rationalize expectations, and constantly evaluate their own behavior. For example, these are individuals who imagined that 1 year after the death of their child they would be enjoying dinners with friends again and can quote examples of how they are now doing this. "Okay" describes parents who do not expect to get much better but have a sense of well-being that the worst is over. The events of the death no longer dominate their life. "Good" describes parents who have emotionally relocated the child and are moving on with life. Their memories of the child are secure and they have placed death in some "frame of meaning." Although they may think about their child every day, it is not the lens through which they view all other daily activities.

Twelve children (32%) were either organ or tissue donors or both. In reviewing this process, families were generally glad to have donated. However, there was concern expressed mainly by parents of tissue donors over not being allowed information about the disposition of organs. Families regretted not receiving an acknowledgment from the recipient family. Most families whose children were organ donors had received detailed but anonymous recipient information. Some parents who did not choose donation expressed delayed regret for missing the opportunity to donate their child's organs. Regardless of whether parents elected to donate their child's organs, 80% felt that the discussion led by the organ procurement organization was as kind as possible under the circumstances. In the statistical evaluation, declining to donate organs had no influence on parental responses to other support systems, and donating organs had no influence on the selfreported adjustment of parents.

Parents were asked whether "A church/temple/synagogue has been very helpful to me and my family since the death of my child." About half (26 of 54 [48%]) of parents replied yes and 24 of 54 (44%) replied no. Forty percent of parents regularly attended religious services before the child's death, and 40% continued to attend religious services after the child's death. Three parents changed faiths. Only two parents stopped going to church and six started to attend church. Nineteen parents felt that a minister had significantly helped them through their grieving process. Of interest, there was a significant discordance between mothers and fathers in their responses to all questions concerning religion, with mothers far more likely to rely on spiritual support services for help (n = 5 questions, p = 0.000-0.032).

Table 5 lists parents' assessments of the lasting effectiveness of the dinner meeting and support network. There was a significant concordance between mothers and fathers in their responses to all questions concerning the support network (n = 4 questions, p = 0.000-0.001). When asked who had helped the most with personal grief, both mothers and fathers most often said clergy, with mother-in-law being the second most common response.

Supporters	Yes (%)	No (%)
Take actions to remember child	34 (63)	12 (22)
Accepted time needed to adjust	27 (50)	6 (11)
Call, visit, take out, and write often	17 (31)	14 (26)
Dinner meeting of ongoing benefit	36 (77)	4 (9)

Table 5 Final Interview (54 Parents/37 Families) Observations on the Support Network

Another issue addressed at the final interview included the parents' marital status before and after the child's death. Of the 37 families that completed the final interview, 29 have ongoing marriages or relationships. Three parents were not in a relationship at the time their child died and five parents are not in the same relationship. Of those that are not in the same relationship, we asked the question "Was the breakup caused by your grief?" One parent answered no, three answered yes, and one was undecided. On the basis of these replies, there was approximately an 8% divorce rate attributed to a child's death.

Qualitative reports typically do not generate answers but rather generate narrative accounts, explanations, and conceptual frameworks.7 Additional relevant observations follow in the discussion.

DISCUSSION

Despite our best efforts to improve advocacy efforts for injury prevention, unintentional injury remains the leading cause of death in children in the United States. It is estimated that 80,000 parents are newly bereaved by violent death each year, including accidents, homicides, and suicides.⁸ Many of these children will die in emergency departments, and some will be resuscitated, only to die within hours or days later. Health care providers who work in emergency departments and critical care units have a personal and professional responsibility to support surviving family members. Formal training in compassionate care for either physicians or nurses is typically lacking in standard curricula. As a result, many health care providers are fairly abrupt in their approach to "giving bad news," as there is a natural tendency to avoid difficult and emotional situations. Particularly in the case of emergency department deaths, the only contact will be very brief, with little or no time to prepare.⁹ However, the individual who tells the family about the death will become a permanent part of the surviving family's memory. If the behavior of the professional at this critical time is uncaring or misleading, there may be subsequent harmful effects on the family's adaptation to the loss of their child. Most survivors desire compassionate care in the form of empathy and truthfulness, and a structured, multidisciplinary approach combined with staff sensitization and education can benefit both surviving family members and hospital staff.¹⁰ First impressions are hard to undo, and bad news should be given in a quiet, private place rather than in a public waiting room. Language should be simple, directed, concise, and honest.

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Wherever or whenever the death occurs, there should be an opportunity provided to see, hold, and touch the deceased child in a private setting, permitting the parents to say good-bye.11

The ability of a professional to meet the needs of a family in crisis may be compromised if he or she has personal difficulty coping with a death. Physicians may view a failed resuscitation as a personal failure, even if the resuscitation was technically perfect. The need to know that "everything that could be done was done" becomes a need not only for the family but also for the provider. The abrupt shift from providing physical and cognitive skills of resuscitation to providing a very emotional communication with the family may be difficult for most providers to achieve.² If the child survives the initial resuscitation, it does allow some time for establishing a relationship with the family. Intuitively, this may allow for some adjustment time on the part of both medical professionals and the family, but it also can predispose the family to unrealistic expectations unless medical personnel are completely and compassionately honest.

Perhaps the most unique feature of the BIP is that it is a hospital program that adopted the initiative to go to the parent. Most hospitals that offer bereavement services do so via telephone, postal service, or provide invitations to come to the hospital for a support group or memorial service. This, although helpful, requires the parents to do most of the work to get the help. Historically, characteristics of families lost to follow-up are lack of strong family support and trauma as the cause of death.¹² In our program, the hospital brought the program to the parents, and also sought to identify a group of supporters for the parents that would "own the initiative to go to the parent." In doing so, some insightful concepts were gleaned about topics that have been uniquely problematic.

Brain Death

Brain death is a nearly universally misunderstood concept. This misunderstanding is one of the primary sources of parental grief-related guilt. The terms "brain death," "coma," and "persistent vegetative state" become conceptual synonyms in the minds of parents as time passes. To add to the confusion, television and movies will use these terms interchangeably. In popular or lay media there is very little that reinforces what brain death really is. A friend or family member or stranger may tell the parents that they know of someone who was "brain dead" but is now perfectly normal. From the parents' position, brain death determination means that someone (who may be a new physician never seen) comes to do some tests to determine "brain death." After the tests conclude that their child is brain dead, the child looks exactly the same to the parents.

One benefit of the BIP is that more time could be devoted to explanations of brain death. Many parents had a lasting feeling of guilt that they had somehow guit or given up too soon and had contributed to killing their child. Without exception, parents felt immediately better when they finally

understood what brain death is and that "waiting a little longer" would not have made any difference. Potential remedies for the in-hospital provider include pictorial references to brain injury that use pictures of the brain and determination procedures. Pamphlets that describe brain death in lay terms could be provided to the family before they leave the hospital. It may be appropriate in some circumstances to show the parents results of tests that substantiate brain death, or to allow select family members to witness the clinical tests. Such inclusion is somewhat similar to the inclusion of family members during resuscitation.^{13,14}

Tissue/Organ Donation

In most cases, the decision to donate organs in the acute setting is probably not an intellectual one. Unless the family has made the decision to donate before the injury, the decision to donate is determined by how they feel about it at the time. Therefore, the approach to donation is best done by the person most trusted by and bonded with the family and who understands donation basics. The parents "on the fence" will be less inclined to grant consent if the person asking is a stranger and lacks compassion.

Parents often say no because they had not thought about donation much previously, especially in relationship to their child. They often feel that the body of their child has been violated by the trauma and that organ donation will only violate it more. As parents, they have a need to protect their child. The process of reframing the decision in terms of organ donation giving meaning in the midst of a meaningless event takes some time, perhaps more time than when the child is in the hospital. Perhaps the regret some parents feel later is because of the passage of time and the struggle for meaning that occurs after the death of the child.

Another issue that surfaced during the interview process was that of organ disposition. If a child is an organ donor, our organ procurement organization provides parents with detailed but anonymous information on organ disposition. When the child is a tissue donor (e.g., heart valve donor), the family expects the same recipient information that heart donor families receive. For "valve donor families" they *have* given the heart. Not knowing the disposition of the valve is the source of considerable consternation for many of them. Unfortunately, since tissue preservation is quite different from organ donation, most heart valves will be processed, and may be on a shelf for a time; thus, it is less feasible to provide donor families with recipient information.

Parents

A combination of prospective and retrospective interview studies suggests that approximately two thirds of bereaved persons have a good outcome in the long term, but survivors of persons who die unexpectedly have a poorer mental health status than those of persons whose deaths are more expected.^{15,16} The definition of a "good outcome" has at least three aspects: a return of feelings of well-being, a regained capacity to cope with problems of everyday life, and a decline in preoccupation with grief.¹⁵

In this study, 32 of 54 (59%) bereaved parents were subjectively doing well enough to meet these criteria from 1 to 5 years later. In our previous study evaluating the outcome of parental grieving, only 7 of 29 (24%) bereaved parents were recovering from their grief in a manner generally hoped for by grief experts over a similar time span.⁵

Divorce

Different sources estimate that as high as 50% to 90% of all bereaved couples are in serious marital difficulty within months after the death of their child,^{17,18} with divorce and separation rates ranging from 23% to 70%.¹⁹ More recent information suggests that 72% of parents who were married at the time of their child's death are still married to the same person, and that only 12% of marriages ended in divorce.²⁰ In our study, 78% of couples are still married or in the same relationship as when the child died, and only 8% of the relationships ended in a divorce that was attributed to the grief process. Although divorce in our society is certainly a reality, stories of disturbingly high divorce rates among bereaved parents is a myth that can be counterproductive to the grieving process.

Support Network

Grief is by nature social, and grief resolution requires interaction between the bereaved parent and the communities of which they are a part.²¹ Initially, the family is overwhelmed with attention and care, to the point where they feel emotionally drained. As family members and friends reinstitute their daily routines and the crowd of comforters "thins out," the family may begin to suffer from lack of care.²² Supporters do not overtly make a decision to quit caring. Once they resolve their grief, they often assume that it is time for the parents to be over it, too. This projection misses the significance of the parents' loss. The educational component of the program is designed to make supporters understand that the acute phase of parents' grief may last a year or more, but parental bereavement has life-long ramifications. One of the most important goals of the educational meeting is to help supporters empathize with parents (i.e., to see the grief as the parents see it). To the degree that this occurs, supporters will establish as a reference point the ongoing long-term needs of the parents and not their own internal needs.

A common outcome of bereavement that has been described is the detachment of survivors from family relationships.¹⁹ Reasons for this include the following: family members have difficulties sharing their grief because of pain or embarrassment; withdrawal out of fear that a parent or sibling will also leave them; and an avoidance of the discussion of death with young children to protect the child.¹⁹ In our study, parents were often surprised by which family and friends emerged as supporters and the "anticipated supporters" who failed to come through. The most common valued supporter was a member of the clergy, with mother-in-law the second most common response. One hidden benefit of the program was that many supporters separately commented that the dinner meeting helped them with their individual personal problems and made them think about things in a different light. Comments that supporters and parents made that might have improved our program included the following: to provide handouts for reference, to send out a mailer before the dinner so that people would know what to expect, to include children in the dinner meeting, to invite someone as a guest speaker who had been through this type of loss, and to provide a list of places and professionals (e.g., psychiatrists) to help those who were coping poorly.

In American culture, clergy have typically been relied on to provide grief care. In many areas of the country this remains an expectation among parishioners. Religion offers an institutional framework that structures and promotes interaction and support, bolsters self-esteem, and helps people cope with the effects of negative life events.¹⁹ Clergy are expected to visit parishioners in their home and to offer comfort, direction, and counsel after a loved one dies. Bereaved parents welcomed the participation of clergy in their lives. In contrast, some of the most disappointment experienced by parents occurred when clergy (and the community of faith) failed to meet the expectation of care parents held for them. Some clergy seem to view themselves as the purveyor of grief rituals (e.g., funeral, memorial service) rather than grief care/counseling. Such differing expectations of the clergy's role may explain why some clergy believe they have met the parent's requisite needs whereas parents feel disappointed in the response.

Other Issues

There are two other prevailing issues that should be mentioned. The first is that many parents need to settle how their child died. For example, the parents of a child that fell onto a knife needed to know where the knife entered and what damage it had done. Until this information was provided, they could not imagine how such a small knife and wound could lead to the death of their son. This is revealing in that explanations at the hospital, particularly in the emergency department and regardless of how well done, do not penetrate the shock and disassociation experienced by the family. Many parents have significant questions that affect their grief, but feel impotent to pursue the answers once they have left the hospital behind. In these circumstances, a follow-up telephone call by someone who was involved in the child's resuscitation and/or subsequent care would provide an opportunity for parents to discuss unanswered questions.¹

The second issue is that many parents want every item of clothing that the child was wearing. Most of these requests come from mothers. Unless the coroner has concerns, it is appropriate to preserve all clothing and personal effects of the child and return them to the parents.

On the basis of our observations, it would appear that more formal education of health care personnel to include compassionate care principles, the conceptualization of brain death and organ donation, and how to counsel survivors after a child's death would be worthwhile. It is also clear that many families have unanswered questions about the medical care that was provided to their child, but are immobilized when it comes to asking for clarification. Parents benefit the most when someone interprets the process of health care. Under ideal circumstances, a trauma family coordinator could stay with or shadow the most critical patients from admission to discharge.³ Since this is not feasible in most trauma centers, it makes sense that the teaching of effective communication and compassionate care must be included in the curricula of every level of health care professional. Precedents have been described in some disciplines, providing opportunities for integration and expansion into course structures.²³⁻²⁸ This includes the concept of critical stress debriefing of staff members.29

After unexpected and sudden pediatric death, it has been said that over time, most parents are able to regain their previous level of functioning.³⁰ Although 59% of parents in our study described their recovery as "okay" or "good," the concept of "normal life" for parents was challenged by the need to establish a new sense of normal. From our experiences, we learned that parents want to help us humanize our care of patients and themselves. They, by their unfortunate experiences, are our best teachers.

REFERENCES

- Ahrens W, Hart R, Maruyama N. Pediatric death: managing the aftermath in the emergency department. *J Emerg Med.* 1997;15:601– 603.
- Dubin WR, Sarnoff JR. Sudden unexpected death: intervention with the survivors. Ann Emerg Med. 1986;15:54–57.
- Jurkovich GJ, Pierce B, Pananen L. Giving bad news. J Trauma. 2000;48:865–873.
- Barrett RK. Unresolved grief and urban youth violence. Forum Newslett. 2000;26:1–3.
- Oliver RC, Fallat ME. Traumatic childhood death: how well do parents cope? J Trauma. 1995;39:303–308.
- Willis RW. Bereavement management in the emergency department. J Emerg Nurs. 1977;3:35–39.
- Giacomini MK, Cook DJ. Users' guide to the medical literature: XXIII. Qualitative research in health care A. Are the results of the study valid? *JAMA*. 2000;284:357–362.
- Murphy S. Cognitive problems among parents bereaved by the sudden violent deaths of their adolescent & young adult children. *Maddvocate*. 2000:10–15.
- Dear S. Breaking bad news: caring for the family. Nurs Stand. 1995; 10:31–33.
- Adamowski K, Dickinson G, Weitzman B, et al. Sudden unexpected death in the emergency department: caring for the survivors. *Can Med Assoc J.* 1993;149:1445–1451.
- 11. Antonacci M. Sudden death: helping bereaved parents in the PICU. *Crit Care Nurs.* 1990;10:65–70.
- 12. Cohen GJ. Children dead on arrival: predictors of short-term family follow-up. *Am J Emerg Med.* 1984;2:315–320.

- Meyers TA, Eichhorn DJ, Guzzetta C. Research: do families want to be present during CPR? A retrospective survey. *J Emerg Nurs.* 1998; 24:400–405.
- 14. Meyers TA, Eichhorn DJ, Guzzetta C, et al. Family presence during invasive procedures and resuscitation: the experience of family members, nurses and physicians. *Am J Nurs*. 2000;100:32–42.
- 15. Lundin T. Long-term outcome of bereavement. *Br J Psychiatry*. 1984;145:424–428.
- 16. Parkes CM. Determinants of outcome following bereavement. *Omega*. 1975;6:303–323.
- 17. Schiff HS. *The Bereaved Parent*. New York: Penguin Books; 1978:57.
- Stone HW. Grief ministry in transition. J Pastoral Care. 1996; 50:269–273.
- Reed MD. Sudden death and bereavement outcomes: the impact of resources on grief symptomatology and detachment. *Suicide Life Threat Behav.* 1993;23:204–220.
- NFO Research, Inc. When a child dies: a survey of bereaved parents. *Forum Newslett*. 1999;25:1 and 10–12.
- 21. Klass D. *The Spiritual Lives of Bereaved Parents*. Philadelphia: Taylor & Francis; 1999:52.
- Oates WE. Pastoral Care and Counseling in Grief and Separation. Philadelphia: Fortress Press; 1976:73.
- Greenberg LW, Ochsenschlager D, O'Donnell R, et al. Communicating bad news: a pediatric department's evaluation of a simulated intervention. *Pediatrics*. 1999;103:1210–1217.
- 24. Leash RM. *Death Notification: A Practical Guide to the Process*. Hinesburg, VT: Upper Access, Inc; 1994:208–226.
- 25. Mian P. Sudden bereavement: nursing interventions in the ED. *Crit Care Nurs.* 1990;10:30–40.
- 26. Shields CE. Giving parents bad news. Oncology. 1998;25:381-390.
- 27. Tye C. Qualified nurses' perceptions of the needs of suddenly
- bereaved family members in the accident and emergency department. J Adv Nurs. 1993;18:948–956.
- Wells P. Preparing for sudden death: social work in the emergency room. Soc Work. 1993;38:339–342.
- Miles MS, Perry K. Parental responses to sudden accidental death of a child. CCQ. 1985;8:73–84.
- Back KJ. Sudden, unexpected pediatric death: caring for the parents. *Pediatr Nurs*. 1991;17:571–575.

DISCUSSION

Dr. Gregory J. Jurkovich (Seattle, Washigton): My thanks, first of all, to the program committee for the privilege of discussing what I find to be a wonderful addition to this year's program.

In Dr. Lewis's presidential address 2 days ago, he referred to the three great challenges for medical care for the new millennium: cost control, competency assurance, and what he termed "consumerism," meaning the need for patient-centered care.

Mary Fallat, Ron Oliver, and their colleagues from the Pastoral Care Service at Children's Hospital in Louisville have provided us with a stunning example of patient-centered care.

The stated purpose of this investigation was to examine ways of helping surviving parents and family members cope with the traumatic death of a child. The unique feature of this work was the fact that this was a program developed by hospital-based chaplains, but that this program was taken out of the hospital to the home of the parents. This bereavement intervention program was organized around four chaplain/parent interactions that remarkably included attending the child's funeral, arranging an educational dinner with parents and supporters and, finally, conducting an in-home interview 1 year later.

As the authors state in the manuscript, "Health care providers have a personal and professional responsibility to support surviving family members." This demonstrates, in my mind, the deep understanding that the term "health care provider" extends beyond the domain of simply disease control and more accurately reflects the meaning of the term "physician" or "healer."

The authors noted that approximately 50% of parents completed the bereavement program in a role from beginning to end. The results in general reflect a remarkable satisfaction on the part of the parents with the empathy and support of the hospital staff, chaplain, and their supporters.

Perhaps most germane to this audience, however, is that the authors have identified areas in which the hospital staff could improve parent/physician interactions; namely, better communication regarding the meaning and significance of brain death and careful discussions regarding organ donation and its implications.

These are clear areas in which the physician can make a difference. Surrogates for the primary care physician will not suffice. Although this study and the authors are to be applauded for the effort, I am left, however, with several questions and an unresolved sense of accomplishment.

Does this bereavement program work? Have the authors convincingly identified ways in which they can help parents through the grieving process? Is a 50% participation rate the best that can be expected?

How can this be improved? Are the authors satisfied with the parents' observation that 31% of their supporters call or visit more often or that 63% of supporters take actions to remember the child?

Was this response rate of supporters improved after the intervention program? Did the bereavement program help the parents work through the grieving process in a normal, healthy manner?

These questions, of course, would ideally be answered in a prospective intervention program. They would have a control group that would not receive the intervention program and a study group that would receive the bereavement intervention program.

These two cohorts would then be studied at a later date to evaluate the efficacy of the program. Would this be an appropriate study to undertake? Is it ethical? Who would fund such an effort?

The American Trauma Society has embarked on an educational program for health care providers called "The Second Trauma." It is a program aimed at educating doctors and nurses in the giving of bad news and the compassionate support of surviving family members of patients who have died from a traumatic death. How would the authors envision incorporating the results of their study into a student or resident education program?

The manuscript touches on many other issues, including the impact of the death of a child on divorce rates and helpful insights into the giving of bad news and the grieving process.

I will conclude with once again congratulating the authors on a remarkable outreach program. Like any good study, it has raised many questions that remain unanswered, but it has affirmed the doctor/patient bond is a strong one, that the ability to communicate clinical details in an empathetic and sensitive fashion matters, and that health care is not just disease care.

We, as physicians, are witness to the most emotionally laden moments of the human journey through life. It is a privilege of our profession. We should make the most of it, and this study has shown us yet another opportunity to do so. Thank you.

Dr. Arthur Cooper (New York, New York): Congratulations on a wonderful study. I have two questions. First, did you find that family presence during resuscitation was either beneficial or detrimental in terms of the grieving process? Second, did you find that the presence of the primary care physician, in this case the trauma surgeon, at the follow-up visit at the funeral home, or at the follow-up dinner 1 month later, added a dimension that the pastoral care staff could not?

Dr. Richard J. Mullins (Portland, Oregon): I join Dr. Jurkovich in complimenting Dr. Fallat and colleagues on an informative and insightful presentation on an important, yet commonly neglected, topic. There is no personal challenge more difficult for me than delivering the bad news to grieving parents regarding a trauma patient who has died. I have a few questions regarding your methods. Does your process of follow-up by the Pastoral care team incorporate the surgeons or other physicians directly involved when the patient died? Do you involve siblings in bereavement interventions and are they invited to the dinner? Do the brothers and sisters of a deceased child have unique stresses from those experienced by parents? Do you have interventions that specifically help the siblings?

Dr. Fernando A. Rivera (Albany, New York): Were the parents given the results of the autopsy? If so, did they find that information helpful?

My last question relates to the place where they died. I think we always try to bring these patients up to the intensive care unit and keep them alive for a while. Did families find that their grief was worse if the child was pronounced dead in the emergency room or the operating room compared with the intensive care unit?

Dr. Jeffrey S. Hammond (New Brunswick, New Jersey): I very much appreciated this study and I appreciate the fact that the Society put it on the program. I think it is probably one of the more important presentations I have heard here.

I have two questions. In our own attempts to put together a bereavement program, we have tried to put together a bereavement box of mementos. This is done in conjunction with the family. This is done mostly out of the intensive care unit rather than the emergency department, but do you have such an effort, and if so, what do you put in the box or try to contribute?

The second question actually derives from Dr. Mullins' comments about the difficulty of being the giver of bad news. Most critical incidence stress teams that I know of in the country and certainly in our state are prehospital—fire, police, emergency medical services—and not hospital directed. As a result of this, we have found the need to create our own Critical Incident Stress Management team internally for hospital-based personnel. Is that the case with your bereavement program? Is the CISM team activated as well?

Dr. Mary E. Fallat (closing): This bereavement intervention program is a sequel to a previous program evaluation that we did in Louisville where we determined, on the basis of grieving indices, that approximately 76% of parents were *not* grieving in a way that grief experts would predict was "normal or healthy." Although the current program cannot be directly compared with the first program, approximately 59% of parents that participated in the current bereavement intervention initiative had what we perceived to be a healthy grieving process.

To design a study that would be ethical would necessitate having some type of intervention where parents were educated about either an Internet site or an 800 number. This would allow them some exposure to the resources available to them, although they might not have the direct personal interaction. On the basis of the literature, there certainly is enough information to suggest that parents need some guidance about the grieving process, what to expect, and where to get help and advice.

I would like to echo the comments that there are organizations that are taking an active interest in compassionate care and grief counseling. We have an opportunity, for example, with courses like Advanced Trauma Life Support, to add some representative scenarios or educational materials that would give advice to trauma surgeons about how to counsel families after a death.

Dr. Cooper, we allow family presence during resuscitation in our pediatric intensive care unit. We have not incorporated this dimension into acute trauma resuscitation in the emergency department.

Those parents in the intensive care unit who observe their child's resuscitation are overwhelmingly positive about the experience, but we have had no critical evaluation of this process in our institution.

Although as a practitioner I give my phone number to the individual who seems most composed when I speak with the family, particularly in the emergency department, I have yet to have anyone take advantage of the opportunity to call me and ask retrospective questions.

Dr. Mullins, your first question relates to a surgeon's personal ability to communicate with the family. A corollary

is, How do we teach our residents and staff about this topic? We have tried to communicate information like this through resident conferences and grand rounds, emphasizing appropriate and inappropriate approaches and statements.

When I am operating on a child that is critical, I make sure that I have a direct link to pastoral care. A chaplain should be with the family. I give ongoing updates of care to the chaplain and family from the room. I often leave the operating room to speak with the family if I feel the child will die, to give them some preparation for the event. In other words, I try to have an ongoing dialogue with the parents in some way so that the death is not a complete surprise.

The second question relates to siblings. We do have an approach for parents concerning surviving siblings. We give them advice about how to tell other children about the death. We also supply them with a video that they can watch to help with their children. We have not at this point included siblings in the meetings. One criticism of the program by parents and supporters related to not including children in the program.

Dr. Rivera, the autopsy information is provided to the family if they would like this information. If you are able to acutely resuscitate the child, this allows you to admit the child to the intensive care unit and allows parents to have a little more time to adjust to the fact that their child is going to die.

Time also may have some influence on your ability to develop a relationship with the parents; it allows them to call on and have more supporters at the hospital when death occurs, and may improve organ donation potential.

In response to Dr. Hammond, the first question relates to a "momento box." We do try to collect all clothing and all personal effects and return them to the parents. In addition to the videos that I have previously mentioned, we have a variety of brochures and a packet of information that we give to parents. We have also developed a grief care information center with an 800 number. This is a resource they can access after they go home and have a chance to think about what happened and what questions they have.

The second question relates to critical incidence stress debriefing, and we do have a team that can be mobilized as needed. This process takes its greatest toll on emergency department and pediatric intensive care unit personnel. The team is available as needed to deal with specific incidents.