

# Parental Perspectives on Hospital Staff Members' Acts of Kindness and Commemoration After a Child's Death

Mary Ellen Macdonald, PhD\*; Stephen Liben, MD\*; Franco A. Carnevale, RN, PhD‡; Janet E. Rennick, RN, PhD§; Susan L. Wolf, BA\*; Donald Meloche, MA, LTH, DMIN||; and S. Robin Cohen, PhD¶#

**ABSTRACT.** *Objectives.* Acts of kindness and commemoration by staff members often follow the death of a patient. Acts include attending funerals, sending sympathy cards, sending cards on birthdays/anniversaries, telephoning/visiting family homes, and attending memorial services. This study explores the significance of these acts for bereaved parents.

*Methods.* Twelve parents whose children died in the ICU of a tertiary care pediatric hospital were interviewed, to explore their experiences of the death. Investigators reviewed transcripts and observational field notes. Multidisciplinary team triangulation was used to corroborate themes, with cross-case analysis.

*Results.* Three themes emerged regarding parental experiences of staff members' acts, ie, (1) parents placed great importance on the hospital's memorial service and on staff members' presence at the service; (2) parents found it difficult to return to the hospital after the child's death but all attended the memorial service, finding some closure in the return; and (3) parents appreciated receiving cards and greatly valued staff members' efforts to telephone/visit and to attend the funeral. Months later, parents remembered positively which staff members engaged in which activities. Conversely, parents expressed disappointment when staff members did not engage in these activities and/or were absent from memorial/funeral services.

*Conclusions.* Efforts to support families and to commemorate deceased children are appreciated by bereaved parents. Staff members' absences at commemorative events and a lack of supportive acts are noticed and regretted by families. Staff members and program administrators should attempt to arrange workloads to ensure meaningful contact between staff members and parents during the bereavement period. *Pediatrics* 2005;116:884-890; *PICU, bereavement, child, palliative care, parental perception.*

Although many health care professionals make efforts to commemorate the death of a patient and to support the bereaved family, literature acknowledging and evaluating such acts is scant. When medical and allied health research does mention acts of kindness and commemoration, generally the focus is on descriptions and evaluations of or recommendations for bereavement interventions from staff perspectives<sup>1-8</sup> or on ritual and grieving more generally.<sup>9,10</sup> Focus is rarely on how families experience staff efforts after the death of a child.

Memorial services are becoming more common in some adult health care institutions (eg, in HIV hospices), where they serve both to aid family bereavement and to support health care workers.<sup>11</sup> Memorial services are also becoming common in palliative care programs<sup>12,13</sup> and in renal units.<sup>14</sup> Literature on memorial services appears rarely in pediatrics and what does exist generally is associated with hematology/oncology units,<sup>1,15,16</sup> rather than general pediatric care.

According to a study by DeCinque et al,<sup>1</sup> bereavement programs vary greatly between institutions and are not evidence based. The authors examined bereavement services in 9 pediatric oncology units and concluded with a call for more research on the needs of bereaved families, as well as on services and evaluation methods that could be implemented as "best practice" for hospital-based bereavement programs.

This article reports on one aspect of findings from the first phase of a 3-phase study to explore the experiences of families confronted by the life-threatening illness of a child. The goal of phase 1 was to understand more completely the experiences of parents whose child died in the PICU of a tertiary care, university, pediatric hospital. Phase 2 is a prospective ethnographic study of critical illness and is underway currently in the same PICU where these children died. Phase 3 will involve returning to the phase 1 sample with findings from phase 2, to ask for additional comment and elaboration from parents. Future articles from phase 1 will address themes such as the place of both positive and negative experiences of the PICU in parents' memories, how parents understand autopsy and their experiences waiting for autopsy results, the place of memorabilia (eg, photographs and medical charts) in family be-

From the \*Pediatric Palliative Care Program, ‡Critical Care, §Department of Nursing, and ||Pastoral Services, Montreal Children's Hospital of the McGill University Health Centre, Montreal, Canada; and Departments of ¶Oncology and #Medicine, McGill University, Montreal, Canada.

Accepted for publication Jan 13, 2005.

doi:10.1542/peds.2004-1980

No conflict of interest declared.

Address correspondence to Mary Ellen Macdonald, PhD, Pediatric Palliative Care Program, A413, Montreal Children's Hospital of the McGill University Health Centre, 2300 Tupper St, Montreal, Quebec, Canada H3H 1P3. E-mail: mary.macdonald@elf.mcgill.ca

PEDIATRICS (ISSN 0031-4005). Copyright © 2005 by the American Academy of Pediatrics.



reavement, and the role of medical technology and heroics in parental bereavement.

## METHODS

### Design

A qualitative method was chosen because this study has a descriptive and explanatory aim, seeking the subjective understanding of families and hospital staff while focusing on increasing the evidence base for supportive care and generating ideas for future interventions and study.<sup>17-19</sup> A "focused ethnography" study<sup>20</sup> was conducted, which involved a researcher (M.E.M.) and an assistant (S.L.W.) visiting family homes, where field observations and semistructured interviews were conducted with individual parents in their language of choice (English or French; see Appendix for interview topics). All except 2 interviews were conducted in family homes; 2 parents chose to return to the hospital for the interview. Most interviews were conducted with individual parents. In 1 situation, children were present and listened to some of the interview but did not take part. In 2 situations, a spouse was in the house during part of the interview and participated briefly. In 1 such situation, the spouse was interviewed a few days later. These data collection methods ensured privacy and flexibility, which were both important considerations, given the emotional content of the subject matter being discussed.

### Setting

The subjects were recruited from the PICU of a 160-bed, free-standing, pediatric hospital. The hospital serves a multicultural and multilingual population and is one of only 2 pediatric hospitals in a city of ~3 million. The hospital has a consultation-based, palliative care program (since 1992), with several core members coming from the PICU. The 12-bed PICU is a cardiac and trauma referral center and has 500 admissions per year, a mortality rate of 7%, and an average length of stay of 6 days.

### Participants

The human subject protocol for this project was approved by the hospital's institutional review board. Participation was voluntary, and written informed consent was obtained from all participants. We reviewed mortality statistics for the PICU, and a 15-month sample (April 2001 to June 2002, inclusive) provided 20 families eligible for inclusion. This time period allowed us to seek families who had had a child die in the PICU between 9 and 18 months before recruitment, a period that provides distance from the death but is not so remote as to affect recall ability.

We conducted a chart review to familiarize ourselves with each case and to locate a "staff contact person," that is, a staff member who was familiar with each family and from whom permission to contact the family could be obtained. All families were contacted via telephone or were sent a letter from the hospital bereavement

coordinator (if no telephone number was available). Table 1 explains the recruitment process.

As Table 1 indicates, 8 families agreed to participate and 12 parents were interviewed (8 mothers and 4 fathers). Seven interviews were conducted in English and 5 in French, although many parents were bilingual. All parents were part of 2-parent families, and many had multicultural backgrounds (eg, Greek, Italian, Egyptian, or Caribbean). The only reason for declining participation stated by parents was that they did not want to talk about the death. Because our original goal was to explore "family" perspectives, parents were asked to recruit siblings and extended-family members into the study. No siblings or extended-family members were recruited successfully. Two explanations were given, ie, that the parents did not want their children and relatives to be reminded of the death or that the children and relatives simply were not interested.

Table 2 describes the deceased children. Three had no siblings; the others had 1 to 3 siblings.

### Data Collection

Appraisal of the literature on family experiences of critical illness and the death of a child helped determine interview topics. Topics included hospitalization, interventions, communication, decision-making, family functioning, social supports, and bereavement (see Appendix). A semistructured interview guide was then created with the intention of eliciting family experiences of the illness and subsequent death of the child. The guide was reviewed and reworked by the multidisciplinary research team and evolved as the interviews proceeded, to respond to each parent's particular experiences. The multidisciplinary research team was made up of the principal investigators (M.E.M., S.L., and S.R.C.), a hospital advisory committee (F.A.C. and J.E.R.), a research assistant trained in medical anthropology (S.L.W.), and a chaplain who is also a pastoral counselor (D.M.). This group included clinicians with PICU experience, including a physician (S.L.) and 2 nurses (F.A.C. and J.R.), 1 of whom is also a psychologist (F.A.C.), as well as a medical anthropologist (M.E.M.) and a research psychologist (S.R.C.).

All interviews were conducted by 2 researchers together, ie, a medical anthropologist (M.E.M.) and a research assistant (S.L.W.). Interviews were audio-recorded and occurred in each participant's preferred language (English or French). Interviews were begun by addressing issues of confidentiality, anonymity, and data security, and written informed consent was obtained. Interviews then addressed key topics, using prompts to initiate dialogue and allowing the parent to take the conversation in meaningful directions. Interviews were continued until all topics had been discussed, and they ended with an opportunity for the parent to add any additional discussion topics. Extensive field notes were recorded by both interviewers within 24 hours for all interactions, documenting conversations that occurred when the

TABLE 1. Recruitment

	Recruitment Process	Total Families Recruited	Total Subjects Recruited
No staff contact person identifiable and/or available (5 families)	3 families were sent a letter explaining the study, followed by a telephone call by a bereavement coordinator; 1 declined permission for researchers to contact family and 2 gave no response to multiple telephone attempts		
Contact person available (15 families)	2 families were sent a letter (no telephone number available); neither responded to the letter Staff contact person left message for 1 family; no reply by family 14 families were contacted by staff members; 2 declined permission for researchers to contact family, 1 agreed to contact by researchers but then declined when researcher called, 3 agreed to contact by researchers but then were unable to commit to interview, and 8 agreed to contact and agreed to participate in study	8	12 (4 fathers and 8 mothers)



TABLE 2. Characteristics of Deceased Children

	No. (N = 8)
Gender	
Female	4
Male	4
Age	
<6 mo	3
2–9 y	2
10–18 y	2
>18 y	1
Diagnosis	
Trauma	1
Rare musculoskeletal syndrome	1
Spina bifida	1
Cardiac disease	4
Cerebral palsy	1

tape recorder was switched off and providing descriptions of the family home and the researchers' reflections.

Interviews were transcribed verbatim, in the original language, by a professional not involved with the project. The members of the multidisciplinary team reviewed the transcripts and field notes independently. The team met formally 3 times, and subgroups of team members met more frequently to discuss issues regarding recruitment, ethics, data gathering, and analysis. Data (interview data and field notes) and multidisciplinary team triangulation were used to identify and to corroborate emerging themes, with a framework of cross-case inductive analysis.<sup>21,22</sup> Bias was minimized through data, method, and investigator triangulation; 2 interviewers attended each interview (ensuring "double listening"<sup>23</sup>), 2 data sets (field notes and interview data) were developed, a multidisciplinary team reviewed the data, and interpretation of the data was reached with team consensus, thereby guarding against idiosyncratic interpretations of data.

## RESULTS

### Themes

Several salient themes emerged from the data concerning the role of staff participation in supporting bereaved parents and commemorating a child's death. The themes included (1) parental opinions regarding the hospital's memorial service, (2) parental experiences in returning to the hospital for the first time after the child's death, and (3) parental thoughts about staff members' acts of kindness after the child's death.

### Parental Opinions Regarding the Memorial Service

The memorial service currently in place at this hospital was one of the first in Canada in a pediatric setting. This service is the result of collaboration between a palliative care program and pastoral services. It is multidisciplinary, nondenominational, and multicultural. This service has evolved over 15 years into a service to commemorate all patients who die at the hospital (eg, death resulting from chronic illness, acute illness, or trauma). The service is held 2 or 3 times each year, each time commemorating 40 to 50 children. Personal invitations are sent to the families of each child to be commemorated, and staff members involved in each child's care are verbally invited individually. Written invitations are sent to each hospital ward, with a list, customized for that ward, of the patients to be commemorated. Written invitations are also sent to each medical and nursing department and unit and to senior administration. Notices are posted throughout the hospital. An au-

dience of ~100 people includes bereaved families (60%) and staff members (40%).

The service begins with the lighting of candles; each child's name is read aloud and projected on a screen as a candle is lit in his or her name. Staff members from diverse backgrounds and occupations provide readings and reflections designed to match the profile (age, religion, language, and ethnicity) of the children being commemorated. Musicians provide interludes. Slides accompany both the readings and the interludes. At the end, families are invited to take a white carnation from a bouquet at the front. Coffee and snacks are then provided, allowing time for staff members and family members to mingle together and for family members to meet members of other families, some of whom they had already met during their hospital stays.

All of the parents in our sample attended the memorial service. Given that ~60% of invited parents attend a given memorial service, it is possible that some of the parents who refused to participate in the study might also have refused to attend the service. All of the parents we interviewed had positive things to say about the aesthetic features of the service, and all supported the efforts of the hospital to hold such a service. Parents stated that they "found the service really nice" and that "the ceremony is a 'must.'" (Some identifying features have been disguised in the verbatim quotations, to maintain the anonymity and confidentiality of family and staff members; for example, all quotations are rendered in English, regardless of the original language.) One couple continued to attend subsequent services, seeing them as an opportunity to be reimmersed in memories of their child.

Parents had many positive reflections about the service. As one father said, the memorial services can provide a sense of community.

Well, you know . . . (long pause) I guess it, you know, shows that you're not alone. There's a whole lot of, ah, other kids . . . that their families . . . have the same problems that you have.

Parents told us that they appreciated staff attendance at the memorial service and appreciated staff efforts to take part in the service. Seeing staff members at the service is "nice," according to one mother.

What I appreciated there was to see a few nurses that came to [the service]. They knew we were there, they knew a lot of people who were there, they took care of a lot of little infants, and they wanted to see the parents back. So that was nice to have the opportunity to see them again.

Parents understand that the service is not just for the families but also functions to comfort the grief of staff members. One mother expressed her concern for the staff.

Oh, I don't know how [the staff members] do it, I really . . . So no wonder they have [a service]. . . . My God, I mean (sobbing), they really need to have that. It's important for the staff, just as much as for the families.

The candle lighting emerged as a significant moment for families. Despite there being >50 candles, and despite the fact that coordinating the lighting with the reading of the name is difficult, families know exactly which candle represents their child.



After the service, family members often come to the front to collect the exact candle that was lit for their child. One mother told us about her 9-year-old son, who asked for his deceased sister's candle.

When they place all the little candles and then they say the name of the children . . . [my son] went after to see the chaplain and then told him, "I want the eleventh that was lit."

According to this mother, this sibling keeps the candle and the program from the memorial service in a special place in his bedroom.

Furthermore, the reading of the children's names is significant for families. The same mother told us that, after the service was over, her son felt he had to set the record straight with the pastoral services director and went up after the service to correct the pronunciation of his sister's name, "My sister, she is not called Vivianne, she is called Vivienne."

In one situation, the candle of the deceased child was lit but went out during the service. Despite the best efforts of the staff members involved, the candle could not be relit. It then stood out as the only candle not lit as the service progressed. A pastoral services worker left the hall to retrieve a new candle, returned, and lit it while the service continued. Given the symbolism tied to the candle and the flame, this event could have been interpreted in many ways. An objective interpretation puts the blame on a finicky wick; a more symbolic interpretation might see it as additional bad luck to accompany the bad luck that took the child's life.

The mother of the child represented by this candle followed no such standard interpretations. Instead, she interpreted this event as being *caused* by her deceased child, whom she referred to as "the little trickster." She told us that her daughter was playing a trick on the audience, that she had blown out the candle herself.

This was [my daughter's] personality. I can just see her (mother makes a blowing sound, pretending to be the child blowing out the candle), you know? . . . And, like I said, this was the personality because actually I see her grinning (laughter), you know?

Although all of the parents appreciated that the hospital held the memorial service and were positive about the style of the service, many parents also described negative aspects of the experience of attending the service. Their criticisms were not directed toward the service itself, however; they were more-general commentaries on the experience of losing a child.

For example, parents found it emotionally "hard" to attend the service. One mother told us that, although she appreciated the service, she also felt that she did not really have "a choice" to attend. As a mother, she felt she had to go to any service that commemorated her own child. The experience was "hard" for parents for 2 reasons, first, because any experience related to the child's death is "hard" and, second, because it is overwhelming to participate in the commemoration of the deaths of such a large number of children.

Another reflection was on the generic nature of such a group event. Because the service serves as a

general commemoration for >50 children, it cannot be tailored to each family's needs. One mother felt that, although the service served an important function, her child could not be commemorated adequately in a group setting.

This was for a group of children. [My child] was included. But she was unique and it didn't really . . . It's good for some of the parents. See, I, I understand that, but I see it wasn't her. . . . I didn't cry for that memorial service at all because it wasn't [my child's] service. It was [all] the children's service. And, for [my child's funeral] service, I did cry because, you know, it, it was very moving.

In contrast to the positive commentaries about seeing staff members in the audience, not seeing familiar faces at the service was also remarked on and, for some parents, resulted in feelings of isolation and loneliness. For one mother who told us that overall she found the service to be "beautiful," not seeing familiar staff members' faces in the audience underscored her feelings of isolation. Her daughter's death was the result of a car accident. Her stay in the hospital was brief and over a weekend, which meant that only a few staff members had gotten to know the family. In the following quotation, this mother posits that perhaps the staff members that were present during her child's admission were simply not at work on the day of the memorial service. This explanation seemed to give her some solace.

And for sure, for the people who their child was sick in the hospital and they were at the hospital often, they know lots of people, and so there were people that were there that knew them. We went and we were like all alone because the people that worked that weekend didn't work that day so they did not come. And they didn't really know [name of child] there.

### Parental Experiences in Returning to the Hospital

Attending the memorial service is obviously wrought with sadness and grief for these parents. Coming to the memorial service presents the added challenge of having to return, in many cases for the first time, to the hospital, the location of the critical illness and eventual death of their child. The return is often fraught with difficult feelings and memories.

This return to the hospital was significant for most parents. Some parents wanted to revisit the actual room where their child died; others did not. Some tried but could not find the strength. For example, one mother said,

I went up [to the ICU] but I couldn't go to the room. No. No. I couldn't. I wanted to go to the ICU, but I couldn't. No. I just made a U-turn and, uh (pause), I can't. I went down and, uh, no, I wasn't able. No.

Another mother said that it was actually easier to go to the hospital than when her child was alive, which underscores how difficult the hospitalization was. Like the mother quoted above, she and her husband did try to return to the ICU; however, they could not bring themselves to enter the unit. Another mother mentioned her appreciation of staff members who offered to meet her outside the ICU.

We went up to the floor, we didn't go in to the intensive care unit itself, and some of the nurses came out and I brought them a little tray of snacks, stuff like that. But it was wonderful seeing some of the nurses again because, like I said, they're like family or friends for, you know, many weeks of our lives,



so it was wonderful to see some of them, and I still have contact with [name of nurse], so you know we talk about the hospital and stuff and I hear about some of the nurses through other moms.

The return to the hospital can also be important for siblings. In the following example, the 9-year-old brother was not present when treatment was withdrawn and the child died. According to this mother, returning to the actual location of the death might play a positive role in his acceptance of the death.

[My son] asked [staff member] to go see where [child] died. . . . And he, I have the feeling that it was like important that he saw all that again so he could say, "I didn't dream that. It's really real that she went there and that she died there."

Returning to the hospital for the service can be instrumental in shifting feelings about the actual hospital building and the part of town where it is located. One mother told us,

Now when I drive by [the hospital], I don't think about it any more. It's funny. When I used to drive by on my drive to work, I'd look at the exit [for the hospital] and I'd say, "Oh," [sound of dread]. You know? I would turn my head and look at the hospital, and . . . [pause]. Since [returning for the memorial service], I haven't. Now that I think about it, I don't look. I just go straight by.

In addition to stirring uncomfortable memories of the death, returning to the hospital can present unforeseen challenges for parents, as this example demonstrates.

It was hard to get inside the hospital. You know, how? You come there and then you say, "Oh my god!" and then, "I have to get in, OK." And then you wonder. You come in and then the first person you see is the guard downstairs. And he looks at you, "Mrs. [family name], where is your car?" I said, "I don't have it." He says, "Where is your car? Bring it, and then I'll park it for you." Because, this is what he used to do. I used to bring [my daughter] with the car . . .

And, sometimes, I didn't have the parking for the handicapped, so I used to disembark [the child] and then the guard would take the key and say, "Leave the car. I'll park it as soon as I get a spot." I said, "I don't have the . . . I don't have [the car]."

And then he asks, he says, "Where is [your daughter]? How is she doing? You haven't, you have [been discharged]?" I said, "She's gone." So, it was kind of, you know, hard.

Then you walk by radiology and you meet [staff member]. She didn't know [about the death]. And she told me, "So [your daughter] is [discharged]?" I said, "No. She's gone." She started crying.

So then you go, you know, step by step. And then you say, "You have to do that. You have to. You have to. You have to put closure to that." So it was hard.

### **Parental Thoughts About Staff Members' Acts of Kindness After the Child's Death**

After a child dies in the hospital, a bereavement follow-up coordinator ensures that there is one staff member available to provide supportive care for the family members in their grief and bereavement. This coordinator also ensures that there is a condolence card available for medical and nursing staff members to sign, with their own personal message. There is no existing guideline for staff members regarding contacting the family or attending the funeral; this is a voluntary personal initiative and depends on the nature and quality of the relationship.

Parents indicated that they greatly appreciated

when staff members conveyed their sympathy in cards or telephone calls. One father had a stack of cards ready to show us when we went to the house to conduct the interview. His wife told us about the contact she continues to have with hospital staff members. Some staff members still call her regularly or send her cards, and one even went to the house for dinner. For her, as for other parents, this demonstrates the "humanity" of these health care workers.

Like noting staff member absences at the memorial service, parents remembered which staff members did not send cards, as revealed in the following exchange.

Mother: Yeah, actually we got a few cards. We got a couple from some of the nurses, quite a few from the nurses; we got one from Dr. [name]. I think [addressing spouse] you were disappointed though, some of the other doctors that we didn't . . .

Father: Yeah.

Parents also noticed and were grateful when staff members attended the child's funeral.

I've never seen a patient, I don't know, who dies and nurses come to her funeral. Nurses from the hospital, on the wards, the physiotherapists. All the . . . The 2 physiotherapists I had to deal with during the stays there, this time and the previous. They showed up [at the funeral]. . . . There, there wasn't one who didn't, you know? Some of them showed up with their [spouses]. I received cards from every and each individual nurse on the ward. . . . And they called. They used to phone [my house] and ask how I am. . . . They were wonderful, the girls.

One mother stressed to us that, despite a snowstorm, staff members made an effort to attend her child's funeral, 1 hour away from the hospital. Another found it significant that staff members attended her child's funeral on a Thursday, therefore having to take time from work. Furthermore, a nurse from the hospital read a poem at the funeral, a poem this mother now carries in her purse. One mother recounted with fondness a doctor who attended the funeral wearing a piece of jewelry that her child had given the doctor as a gift. Both she and her husband listed, without prompting, exactly which staff members attended the funeral and which came to the family home (located 45 minutes from the hospital) after the death. It was especially significant to them that one doctor returned for the mass marking the 1-year anniversary of the death and brought a plant to the house as a gift. This plant was displayed proudly in the kitchen many months later.

Given the overwhelming events surrounding a funeral, parents are not always aware who is or is not in the audience. This lapse of awareness does not mean that it does not matter who is present or absent. On the contrary, one mother told us,

There were so many people there, if [staff members] did [come], I don't even know. And too bad, 'cause I would have liked to know that if they did.

### **DISCUSSION**

Our study was designed to explore the experiences of parents confronted by the death of a child. Several salient themes emerged from the data concerning the role of staff participation in supporting bereaved parents and commemorating a child's death. All of



the family members in our sample appreciated the efforts of hospital staff members to support them and to commemorate their deceased children. Staff member presence at memorial services and funerals was comforting to the families, as was receiving cards and telephone calls, which confirmed previously reported clinical reflections<sup>24,25</sup> and studies in both a neonatal ICU<sup>26</sup> and a PICU.<sup>27</sup> In contrast, not seeing familiar faces at the service or receiving cards and calls was also noticed, a point that many staff members may not realize. Contro et al<sup>28</sup> confirmed this point; families often regard hospital staff as a "second family," and thus the lack of contact with staff members after a child's death can be experienced as a "secondary loss."

The memorial service was particularly significant for parents. Although a collective service cannot give focused attention to individual children, listing each child by name and lighting a candle in his or her memory was meaningful for parents and, according to them, for siblings. The service fosters community by bringing family members and staff members together and forces a return to the hospital, which, although emotionally difficult, has many positive aspects for families.

An important limitation to our study is the fact that families who chose not to participate or who were hard to contact might have had other perspectives. For example, it is possible that those who chose not to participate also might have chosen not to attend the memorial service. Furthermore, we purposely restricted our sample to the PICU, to limit the range of phenomena affecting our data; the extent to which our findings are transferable to any area of the hospital where patient deaths occur remains unknown. Future studies should explore aspects not addressed in this study, such as perspectives of hospital staff members and deaths in adult settings. It was suggested previously that acts of kindness provide staff members "with an opportunity to deal with the 'minigrief' reaction that follows the death of a special patient, and it reduces the adverse effects of unacknowledged, cumulative losses that lead to burnout."<sup>24</sup>

It was recommended previously that attendance at patients' funerals should be encouraged and facilitated as part of the education of medical residents and nurses.<sup>26,29</sup> Our results lead us to support those recommendations. Given the complexity of supporting bereaved families, it is important to provide education and guidance for staff members, to promote self-awareness, therapeutic efficacy, management of professional boundaries, and healthy coping.<sup>28</sup> (This hospital has a designated bereavement coordinator who holds regular educational sessions addressing topics such as personal-professional boundary issues; attendance at these sessions is voluntary, however, and the extent of learning has not been evaluated formally.) In addition, we recommend specifically that staff members and program administrators attempt to arrange workloads so that there can be at least 1 meaningful contact between staff members and parents during the bereavement period. Staff members who do attend a funeral but

are unable to indicate their presence to the family should send a card afterward, to let the family know they were present. Furthermore, better staff communication is necessary to ensure that all staff members (including guards, parking attendants, and cleaning staff members) are aware of the death of each child. This would help keep parents from encountering staff members who did not know of the death and would help ensure timely acts of kindness and commemoration.

Bereaved parents are required to manage a number of highly stressful problems, such as feeling deeply isolated from their surrounding community, reconciling profound ruptures between their lives before versus after their loss, and searching for comforting ways of understanding their child's death.<sup>30</sup> Our findings allow us to speculate that the benefits and challenges of acts of kindness and commemoration reported by parents in this study can affect parental mourning and bereavement favorably by (1) fostering a sense of community with other parents, as well as staff members, (2) promoting positive symbols and language for construing the significance of their child's life, and (3) facilitating a smoother transition from their prior lives to their newly reconstructed futures. These speculations will require additional research.

#### APPENDIX: GUIDELINE TOPICS FOR RETROSPECTIVE INTERVIEWS

Our interview guide was informed by the Parental Perspectives Questionnaire from the Parental Perspectives Study of the multidisciplinary ICU, Children's Hospital Boston (Boston, MA).<sup>31</sup> What follows is a list of the major topics covered in the interview. For a complete list of subquestions and topics in our interview guide, please contact Dr Macdonald.

1. Demographic features.
2. Illness experience.
  - Hospitalization: general experiences in relation to the hospitalization and ultimate death of the child.
  - Interventions: the child's condition in the PICU and the treatment of the family.
  - Communication: the clarity and fluidity of communication between health care professionals and family members.
  - Decision-making: the relationship and communication between staff members and family members regarding decision-making issues and quality of care.
  - Family functioning: how well the family members agreed/communicated/negotiated regarding the child's care in the hospital.
  - Social supports: the kinds of social support available to the family.
  - Physical space: impressions of the hospital structure (eg, architecture, aesthetic features, and cleanliness).
3. Bereavement issues: the meaning and significance attached to the child's illness and death and the resources mobilized by the family and community.



#### 4. Recommendations for improving patient and family care in the PICU.

### ACKNOWLEDGMENTS

This study was supported by the Nicholas Baxter Memorial Fund. M.E.M. is supported by a Canadian Health Services Research Foundation postdoctoral award. S.R.C. is supported by the Dorothy J. Lamont Scientist Award of the Canadian Institutes of Health Research and the National Cancer Institute of Canada, in the latter case with funds donated to the Canadian Cancer Society.

We express our deep appreciation and gratitude to the families who participated in this study.

### REFERENCES

1. deCinque N, Monterosso L, Dadd G, Sidhu R, Lucas R. Bereavement support for families following the death of a child from cancer: practice characteristics of Australian and New Zealand paediatric oncology units. *J Paediatr Child Health*. 2004;40:131-135
2. Laakso H, Paunonen-Ilmonen M. Mothers' experience of social support following the death of a child. *J Clin Nurs*. 2002;11:176-185
3. Buchan D, Clarke K, Devereux L, Rhodes B. A celebration of love and care. *Can Nurse*. 1990;86:22-23
4. Rolls L, Payne S. Childhood bereavement services: a survey of UK provision. *Palliat Med*. 2003;17:423-432
5. Johnson L, Rincon B, Gover C, Rexin D. The development of a comprehensive bereavement program to assist families experiencing pediatric loss. *J Pediatr Nurs*. 1993;8:142-146
6. Heiney S, Hasan L, Price K. Developing and implementing a bereavement program for a children's hospital. *J Pediatr Nurs*. 1993;8:385-391
7. Kaunonen M, Aalto P, Tarkka M, Paunonen M. Oncology ward nurses' perspectives of family grief and a supportive telephone call after the death of a significant other. *Cancer Nurs*. 2000;23:314-324
8. Khaneja S, Milrod B. Educational needs among pediatricians regarding caring for terminally ill children. *Arch Pediatr Adolesc Med*. 1998;152:909-914
9. Romanoff B. Rituals and the grieving process. *Death Stud*. 1998;22:697-711
10. Klass D. The deceased child in the psychic and social worlds of bereaved parents during the resolution of grief. *Death Stud*. 1997;21:147-175
11. Tiamson M, McArdle R, Girolamer T, Horowitz H. The institutional memorial service: a strategy to prevent burnout in HIV healthcare workers. *Gen Hosp Psychiatry*. 1998;20:124-126
12. Rawlings D, Glynn T. The development of a palliative care-led memorial service in an acute hospital setting. *Int J Palliat Nurs*. 2002;8:40-47
13. Foulstone S, Harvey B, Wright J, Jay M, Owen F, Cole R. Bereavement support: evaluation of a palliative care memorial service. *Palliat Med*. 1993;7:307-311
14. Ormandy P. A memorial service for renal patients. *EDTNA ERCA J*. 1998;24:22-24
15. Freyer DR. This work we do: reflections from a pediatric hematology/oncology memorial service. *J Paediatr Hematol Oncol*. 2001;23:213-214
16. Heiney S, Wells L, Ruffin J. A memorial service for families of children who died from cancer and blood disorders. *J Pediatr Oncol Nurs*. 1996;13:72-79
17. Savage J. Ethnography and health care. *BMJ*. 2000;321:1400-1402
18. Pope C, Mays N. Qualitative research: reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*. 1995;311:42-45
19. Green J, Britten N. Qualitative research and evidence based medicine. *BMJ*. 1998;316:1230-1232
20. Morse J, Field P, eds. *Qualitative Research Methods for Health Professionals*. 2nd ed. Thousand Oaks, CA: Sage; 1995
21. Greenhalgh T, Taylor R. How to read a paper: papers that go beyond numbers (qualitative research). *BMJ*. 1997;315:740-743
22. Ayres L, Kavanaugh K, Knafl KA. Within-case and across-case approaches to qualitative data analysis. *Qual Health Res*. 2003;13:871-883
23. Benner P, ed. *Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness*. Thousand Oaks, CA: Sage; 1994
24. Holland J. Management of grief and loss: medicine's obligation and challenge. *J Am Med Women's Assoc*. 2002;57:95-96
25. Wessel MA. The role of the primary pediatrician when a child dies. *Arch Pediatr Adolesc Med*. 1998;152:837-838
26. McHaffie H. Withdrawing treatment from infants: key elements in the support of families. *J Neonatal Nurs*. 2001;7:85-89
27. Macnab A, Northway T, Ryall K, Scott D, Straw G. Death and bereavement in a paediatric intensive care unit: parental perception of staff support. *Paediatr Child Health*. 2003;8:357-362
28. Contro NA, Larson J, Scofield S, Sourkes B, Cohen HJ. Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*. 2004;114:1248-1252
29. Downey V, Bengiamin M, Heuer L, Juhl N. Dying babies and associated stress in NICU nurses. *J Neonatal Netw*. 1995;14:41-46
30. Rando T, ed. *Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working With the Dying, Their Loved Ones, and Their Caregivers*. Champaign, IL: Research Press; 2000
31. Meyer E, Burns J, Griffith J, Truog R. Parental perspectives on the end-of-life care in the pediatric intensive care unit. *Crit Care Med* 2002; 30:226-231

### PUSHING DRUGS—DIRECT-TO-CONSUMER ADS

"In a . . . recent survey of 643 U.S. physicians, many attributed a double-edged effect to pharmaceutical ads. Nearly three-quarters of the doctors said that they believe that DTC [direct-to-consumer] ads inform people about the medicines that might help them, and two-thirds of the doctors said that ads improve dialogue. One quarter of the ad-initiated doctor-patient conversations lead to diagnoses of treatable problems that might have gone undetected, the doctors report.

On the other hand, four-fifths of the survey respondents said that ads encourage patients to seek unnecessary treatments and don't fully convey the therapies' risks. Joel S. Weissman of Harvard Medical School and his colleagues posted the results of the survey on the Web site of Health Affairs in April 2004."

Harder B. *Science News*. July 30, 2005

Noted by JFL, MD