

# Anticipatory Mourning in Parents With a Child Who Dies While Hospitalized

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Even when prognosis is poor and death appears imminent, care of the dying child typically focuses on achieving cure. Parents are often ill-prepared to cope with the grief they experience as their child is dying. Anticipatory mourning allows time to begin grief work prior to the death of a loved one. An exploratory design was used to answer questions in focused semistructured interviews to determine the presence and the role of anticipatory mourning, and to describe the themes expressed by parents. Parents' descriptions of their experiences surrounding the death of their child reveal an environment and a health care team that are often ill-prepared to deal with the impending death of a child. Also described are instances that reflect a compassionate process that positively affects the experience while facilitating appropriate grief work. Offered are recommendations for health care professionals that may assist parents in coping with the death of their child.

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## BACKGROUND AND LITERATURE REVIEW

The death of a child has a profound impact on parents. Emotionally, physically, psychologically, and spiritually, parents feel an enormous toll as they experience such a loss. Researchers recognize that the bereavement of parents seems to be more intense than other forms of bereavement (Knapp, 1986). A recent study of mothers whose children died suddenly found that they exhibited more intense grief than mothers whose child died following a prolonged illness (Seecharin, Andresen, Norris, & Toce, 2004). Often, the aim of treatment for dying children is one of aggressive care leading up to the time of death. Consequently, children and their parents often do not prepare or do not know how to prepare emotionally, psychologically, or spiritually for the impending death. This lack of preparation and perceived lack of experience to provide more effective and

compassionate care is shared by both families and health care staff (Contro, Larson, Scofield, Sourkes, & Cohen, 2004).

Health care providers often find it difficult to discuss end-of-life care with parents and their dying children. With cure as the primary focus and goal, frequently little time and effort are spent preparing for end-of-life tasks and for reconciliation with the fact that a child is not expected to survive (Sahler, Frager, Levetown, Chon, & Lipson, 2000).

*Anticipatory mourning* is the process of emotional preparatory experience leading up to the time of death. Formerly termed anticipatory grief, this term describes not only the process of grief but other processes as well. The phenomenon of anticipatory mourning encompasses seven operations according to Rando (2001): grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing of conflicting demands, and facilitation of an appropriate death. The majority of anticipatory mourning literature describe the process in adults experiencing a loss of an adult person, but there are limited literature and data about children and the impact of successful anticipatory mourning on their parents. Satisfaction with end-of-life care, as reported by parents who have sustained the death of a child, may indeed impact the parental grief response (Seecharin et al., 2004). As the experience begins

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prior to death, preparing for the impending death (hence facilitating the anticipatory mourning process) may impact the experience and subsequent bereavement of parents.

Understanding and facilitating the process of anticipatory mourning for parents are an important function of health care providers. Support to parents during this period appears to be associated with less abnormal or complicated grief after the death (Rando, 1986) and thus has tremendous practice implications for health care providers. Bereavement interventions may begin prior to the death of the child (Carter & Levetown, 2004). The primary prevention of abnormal grief or complicated grief reactions is key in helping parents cope with impending loss. Being supportive to those caring for their child during this time and assisting in steps necessary to process the tasks of anticipatory mourning is a tremendous contribution in assisting parents during a time of crisis (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Waechter, 1987). Waechter believes that recognition of the process itself provides the potential for the professional and personal growth of health care providers. The impact that health care professionals can have on preventing suffering for children and families is significant and is not to be underestimated, according to *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families* (Field & Behrman, 2003).

### Purpose and Research Questions

The purpose of this study, which was conducted in 2001–2002, was to describe the presence (or the absence) and the role of anticipatory mourning in parents who recently experienced the death of a hospitalized child and to determine if there were consistent factors that they described as helpful or detrimental to them during this process. Additionally, this study aimed to determine whether parents who experienced anticipatory mourning felt that the process positively or negatively affected the bereavement period following the death of their child.

This study was designed to answer the following questions:

1. How do parents who have had a hospitalized child die describe the experience?
2. Were parents cognizant of their child's impending death?
3. Did parents experience anticipatory mourning?
4. (If the parent answered yes to Question 3) Which factors did parents find beneficial or

detrimental in helping them cope with the process of anticipatory mourning?

5. Did parents feel that the process of anticipatory mourning influenced bereavement?

### DESIGN

A descriptive design, using focused, guided, semistructured, in-depth interviews, was used to collect data. A set of open-ended questions, developed from a review of the literature (Rando, 1986, Vickers & Carlisle, 2000) and from the researchers' own personal experience in this field, was used to guide the interviews (Table 1). A purposive sampling technique was used to recruit 11 parents who sustained the death of a child during the child's hospitalization, thus comprising a

Table 1. Interview Guide

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- Who was the primary caretaker of your child (mother or father) while he/she was in the hospital?
  - Were you aware that your child was dying?
  - How far in advance of your child's death were you aware that your child was dying?
  - How did you become aware that your child was dying?
  - Did you feel that you acknowledged your child's dying?
  - What are your perceptions about who was in control of your child's care?
  - What is your perception of your child's understanding of his/her condition?
  - What was your understanding of your child's condition?
  - What are your perceptions of what actually happened at the time of your child's death?
  - What fears and anxieties about your child's death did you experience?
  - Were you prepared for your child's death?
  - Did anyone help you prepare for your child's death?
  - Do you feel that you grieved for the loss of your child before your child's death actually occurred?
  - Do you feel that you became detached from your child before he/she died? Did you find yourself visiting less frequently or did it become harder for you to visit your child in the hospital?
  - How would you describe how you thought of your child (e.g., present or past) prior to his/her death?
  - What happened after the death of your child?
  - How would you describe professional support leading up to the time of your child's death?
  - How would you describe the communication between you and the professional staff?
  - What nonprofessional support did you receive prior to your child's death?
  - Do you have any thoughts about what you feel was helpful in terms of facilitating coping with the impending death of your child?
  - Do you have any thoughts about what you feel was not helpful in terms of facilitating your coping with the impending death of your child?
  - Do you have any thoughts about whether you would have liked to have done anything differently?
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homogenous subgroup. The medical records of children who died in a major pediatric hospital within the past 2 years but no sooner than 4 months prior to study initiation were reviewed. The researchers conducted the interviews; field notes were taken during the interview. All interviews were tape-recorded and transcribed by an independent hired (using grant funding for this purpose) transcriptionist. The researchers performed transcribed text analysis, followed by repetitive examination of transcripts for the emergence of themes and subsequent coding of thematic content. After repeated analysis, collapsed themes encompassed broader categories. Demographic information was collected with the aid of a questionnaire (Table 2).

To assure trustworthiness, content analysis was performed by the researchers and a secondary reviewer (Creswell, 1998). The secondary reviewer, who recoded the data and confirmed thematic content, possessed knowledge of the content area and was familiar with qualitative ethnographic data analysis. Lastly, upon completion of the study, two study parents were randomly selected to review the

results, and both confirmed thematic content and conclusions.

## PROTECTION OF HUMAN SUBJECTS

Institutional Review Board approval was obtained from the authors' university and from the hospital where the children's deaths occurred prior to study initiation. Professional staff members involved in the care of the child during the hospitalization made initial contact with prospective parents. Informed consent was obtained from each participant in the sample prior to initiating the interview process. All parents received a copy of the signed informed consent. Interviews took place privately in a confidential environment between the researchers and each parent at a mutually agreed upon location. Parents were informed that should they become emotionally distressed at any time during the interview, they could stop the interview temporarily or altogether. No parent chose to stop the process. Following transcription of the audiotapes, the tapes were destroyed. No identification linking parents or their deceased children to transcribed text occurred, as each parent and each child was given fictitious names for use in the audiotaping, transcription, and reporting of study results.

**Table 2. Demographic Information Collection Sheet**

1. Relationship to child: _____				
2. Your age (in years)				
< 18	18-25	26-30	31-35	36-40
41-45	46-50	51-55	> 55	
3. Marital status at the time of child's death: _____				
4. Age (in years) of spouse/significant other				
< 18	18-25	26-30	31-35	36-40
41-45	46-50	51-55	> 55	
5. Highest level of completed education				
Did not complete high school				
Completed high school				
Some college				
Completed college				
Postcollege				
6. Number of persons living in the household at the time of child's death: _____				
7. Ethnicity:				
White, not of Hispanic origin				
American Indian or Alaskan Native				
Asian or Pacific Islander				
Black, not of Hispanic origin				
Hispanic				
Other or unknown				
8. Do you describe yourself as a spiritual person? _____				
9. Your child's diagnosis: _____				
10. Duration of your child's illness: _____				
11. Age of child at the time of child's death: _____				
12. Number of days your child was in the hospital prior to his/her death: _____				

## SAMPLE

The sample consisted of 11 (9 female and 2 male) parents from a sample of 14 parents contacted. Three potential study candidates declined participation, as they felt that they would be too emotional to discuss the events surrounding the death of their child. No parents interviewed were couples. Eight of the parents' children died in the pediatric intensive care unit (PICU), two in the neonatal intensive care unit (NICU), and one at a general pediatric floor. Nine female parents described themselves as spiritual; both male parents did not. Seven female parents were married and two were single; both male parents were married. Educational level ranged from some high school to completion of college degree. The age of the deceased children ranged from 10 days to 20 years, with the length of illness ranging from less than 24 hours to 20 years. The 20-year-old patient was included in the study as his illness extended throughout childhood and he died at the children's hospital. Hospital length of stay ranged from less than 24 hours to 4 weeks. Diagnoses of the deceased children included prematurity, drowning, respiratory syncytial virus,

**Table 3. Subcategories of Theme 1: Parents' Desire for Detailed Information Explaining Why a Child is Not Expected to Survive**

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- Medical staff does not give enough information or does not say that child may die.
- Nobody wants to confront the fact that the child is dying or may die.
- There is benefit in knowing that a child may die; it helps the family to prepare.
- Discussion regarding prognosis and suggestions for stopping treatment took place.
- Parent had to ask for information or information was not given.
- Health care staff should ask families how much information they desire.

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**Table 5. Subcategories of Theme 3: Physical Presence is Paramount for Parents to Experience Anticipatory Mourning Both Leading Up to and Following the Death of a Child**

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- Being allowed to stay with the child leading up to the time of death was allowed and is helpful.
- Not being allowed to stay with the child is detrimental.
- Being asked if parents want to be present is helpful; parents should have this choice.
- Holding the child before death was allowed and is important.
- Holding the child was not allowed and is detrimental.
- Parents held the child or did not hold the child before, after, or before and after death occurred.
- Being allowed to participate in the care of the child was allowed and is felt to be helpful.

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Hunter's syndrome, heart disease/failure, leukemia, neuroblastoma, and polycystic kidney disease.

### FINDINGS, ANALYSIS, AND INTERPRETATION

Six main themes emerged from the data described by the parents, as shown in Tables 3–8. Each major theme contains subcategories that comprise broader categories. The major themes that emerged as facilitating or impeding anticipatory mourning are as follows: (1) giving of information to parents; (2) the impact of the attitudes and actions of health care professionals; (3) physical presence with the dying child; (4) the location of the child's death; (5) issues of hospital policy, procedures, process, and rules; and (6) the existence of anticipatory mourning and its relationship with bereavement. Verbatim accounts of parents are included as examples of each of the main themes.

#### Theme 1: Giving of Information to Parents

Information, particularly detailed information explaining why a child is not expected to survive, is critical in helping parents prepare for the death

of their child. Parents stated that more information would be beneficial in helping them come to terms with the fact that their child was dying. Sixty-four percent of parents felt that they would have done things differently had they known that the death of their child was imminent. Parents described what they perceived as lack of communication between the health care team and themselves.

The following quote illustrates this point:

I think they knew more than they wanted to tell me. Like the last day, I think they knew, and they weren't . . . they just didn't want to I guess . . . but sometimes they need to prepare that person. I would have been able to deal with it better; I would have been more prepared, my husband would have been there. . . He never would have left her side. You want family there, or the closest person to you, which would be your husband or your wife . . . you want all that. You don't want to be left in the dark.

Five of 11 parents described getting some information about the status of their children but stated that they would have benefited from having more in-depth information about why their children were not expected to survive. In short, they

**Table 4. Subcategories of Theme 2: The Attitudes and Actions of Health Care Professionals Have a Tremendous Impact on How Parents Describe the Experience of the Death of a Child**

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Experience of the death of a child while hospitalized

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- The support of health care staff helps and was provided.
- Parents describe staff as helpful during the dying process.
- Parents describe staff as helpful after the child has died.
- Lack of compassion is sensed by parents.
- Show of compassion is sensed by parents.

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**Table 6. Subcategories of Theme 4: Separate Physical Space Impacts the Mourning Process and is Facilitated by Health Care Professionals Trained in End-of-Life Care Who Can Coach Parents Through the Death of a Child**

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- Separate room was available for the death of the child and was helpful.
- Separate room was not available but would have been helpful.
- Current physical space for the child to die is problematic.
- Someone to serve as a coach through the dying process was helpful or would have been helpful.
- Bereavement package was available and is helpful.

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**Table 7. Subcategories of Theme 5: Routine Hospital Policy, Procedures, Process, and Rules are Detrimental to How Parents Perceive the Events Surrounding the Death of a Child**

- Parents describe routine hospital policy, procedures, process, and rules as problematic for mourning.
- Parents describe the timing of autopsy and the delay in autopsy results as problematic.
- Parents describe bereavement packages as helpful.

expressed a need to have a clearer explanation of why their children were dying. Following is an example that highlights this concern:

I don't feel like I got enough, and I don't know if they felt like I couldn't handle it, or couldn't understand it ... I'm not really sure ... So, I think they could have told me more ... so I don't really know what their reasons were ... maybe I could have been more prepared, because it is pretty hard just knowing in 1 day ... that this was it.

Expressed by several parents is speculation on why information was not more forthcoming from the health care team. Most described that giving bad news is difficult for health care professionals, and that confronting the fact that a child is dying is extremely difficult and a topic that is often avoided by health care staff.

Sufficient information about a child's illness and prognosis was given to several of the parents interviewed. Of these parents, the report of staff giving sufficient information regarding prognosis and chances for survival with or without aggressive care enabled them to make what they felt to be informed decisions about the direction of their child's care. In some instances, this meant continuing aggressive therapies, whereas in other instances, parents reported deciding against further attempts at aggressive care when chances of survival were minimal to nonexistent. There exists no clear explanation, according to parent report, as to why some parents received adequate information to facilitate informed decision making whereas others did not. In addition, parents reported no one particular area in the hospital where staff gave consistent accurate information.

Parents with children who had prolonged illnesses and hospitalizations had similar responses to study questions regarding the experience of anticipatory mourning as did parents whose children were sick for a short period. It was apparent that neither duration of illness nor amount of time spent hospitalized appeared to influence how parents described the experience.

Parents described the failure to acknowledge that a child is dying as detrimental, leaving them with feelings of increased anxiety, anger, and grief, which perhaps might have been avoided. Those appraised of the severity and imminent time frame for death felt that this was beneficial in helping them come to terms with the event and afforded them an opportunity to prepare for their child's death. This time frame, although in some instances only hours, allowed parents time to conduct themselves in ways that made the experience meaningful to them and their dying child.

## Theme 2: Impact of the Attitudes and Actions of Health Care Professionals

The attitudes and actions of health care professionals were pivotal in allowing the process of anticipatory mourning to not simply occur but to actually progress. All parents described the attitudes and actions of staff members as having a profound and lasting effect on their experience surrounding the loss of their child. When this experience was positive (when parents perceived staff as compassionate, sensitive, and intuitive to the parent's needs, yet respectful of privacy), they recalled the experience in a favorable manner. Displays of compassion were described as important to parents. An example follows:

One of the nurses, the one who was encouraging us to take pictures ... of course I was holding him and bawling ... my nose was running constantly, and she just kept wiping it away for me, which is one of the things that ... I mean, they were all so supportive... These are the last memories, sometimes the only memories that we are going to have of our children.

Conversely, descriptions of staff who lacked compassion and conducted themselves in manners that parents perceived as negative, routine, and callous negatively affected the process of anticipatory mourning and were viewed as roadblocks to the mourning process, according to study parents. Reflecting back on the experience with negativity was viewed as detrimental. Visible agitation was observed in 36% of parents as they recalled and

**Table 8. Subcategories of Theme 6: Parents Experiencing Anticipatory Mourning That Impacts Bereavement**

- Parent was aware that the child was dying and experienced anticipatory mourning.
- Parent was not aware that the child was dying and did not mourn.
- Parent does or does not believe that anticipatory mourning impacts bereavement.

described the way they were treated or the way their children were treated.

The following statement describes a situation that one parent considered detrimental to her mourning:

... I think they could have done a better job. They could have explained stuff better. They could have had a better attitude toward it. You're in a hospital with kids that, even after their surgery, if they are 3 or 4 years old, they want to see a smiling face and they want to see a good attitude. And that's how that parent looks at it too ... the better your attitude, the better you're going to take care of something ... That's the only thing that I felt was ... it was someone acting like they didn't care, and if they don't care, they don't need to be there. Or they need to change their outlook and think, "How would I feel if I were in that person's shoes?" {crying}

Some parents rationalized why some health care professionals lacked compassion. Several believed that, in order for health care professionals to routinely work in a hospital environment, staff members cannot become emotionally involved or they would not be able to continue working in such a stressful and emotionally charged environment. One parent described her experience illustrating this rationale:

Compassion is lacking in the hospital, which is always kind of funny, you know. And I know they have to steel themselves because they see it. If they got so involved with each and every case, they would probably have to get out of the profession... I mean, he was a doctor. He was like a White Coat. You know, "This is the information, it's your decision"... They lower their voice; they speak softly; you know. But it's kind of like; it's a job. It's still a job. It's still business and you have to conduct business.

Several parents described having difficulty with how they were approached by health care professionals when asked for consent for autopsy. Parents described the insensitivity of some staff regarding the timing and the presentation of autopsy consent. Although all parents recognized the importance of autopsy, a strong theme expressed by parents was the need for more empathy from the health care team when requesting permission for autopsy.

One participant angrily and tearfully described how she received phone results of the autopsy on her child, who had been buried several days prior. She claimed she would never have buried her child without first retrieving the organs from the hospital so they might be buried with the body. Her description of the event follows:

... I was so upset. I was just mad that he ... because he just talked about it like it was casual, you

know, "I have your child's heart and lungs laying here." And that's how it was, very crude more or less. Kind of heartless, you know. I was astonished. I was baffled ... my mouth was wide open and tears were flowing. No, I think that that was something. I wouldn't have buried her had I known [that my child's body had been returned for burial without her organs intact] {sobbing}.

Several parents expressed anger and resentment at the timing of the autopsy request, describing a callous or insensitive attitude of the health care professional requesting for autopsy consent.

Timely reporting on autopsy results also was deemed important, as described by one parent. This parent stated that the delay in receiving autopsy results prevented his family from achieving closure to the death of their child, stating that this lingering issue left his family unsure of why their child had died and whether her death could have been prevented.

### Theme 3: Importance of Physical Presence With a Dying Child

All parents expressed the importance of participating in the care of their child, although only a few were given the opportunity to do so. Physical presence, whereby parents can be close to their child, was described as being extremely important for parents to experience anticipatory mourning, both leading up to and immediately following the death of their child. Active participation in their child's care allowed for a sense of control and facilitated preparation for the event of death. In spite of the fact that most children were hospitalized for at least 1 week, five of the parents interviewed were not allowed to hold their child prior to death. In addition, actively participating in the care of a dying child helped one parent feel that she was helping her child. The following illustrates the benefit of this experience:

... They thought that the tube was clogged, or it was too small. It wasn't draining right. So the nurse let me actually get in and help her change that tube, which was like, you know, I was actually helping her get better... Like I was a part of everything.

Physical presence at the time of death was extremely important for some parents interviewed. The following illustrates the importance of presence:

So I just stroked his head and I knew that this was the time and needed to tell him that it was okay to go and it was hard to tell him but I did. And I was right there. Everything I wanted it to be it was. I wanted to

be there when he died. That was my prayer for him, God don't let me be in the shower, God don't let me be in the bathroom, don't let me be home on a bath break or whatever. That was my prayer, to be with him {crying}.

One parent described not being present at the time of her child's death as she was asked to wait in a small room outside the intensive care unit during attempts at resuscitation that ultimately failed. Following her child's death, the medical staff described the sensation that a spiritual event had occurred at the moment of the child's death. The mother was devastated that she was not present to witness and experience this event. The following also illustrated the importance of being physically present:

They wouldn't let me in there . . . that way, I could tell her bye and that I loved her, right there at the end, before she actually died, so she could hear me. . . . It would have been hard, yes. But just to be able to be there to say goodbye . . . or, no, to spend the last 2 or 3 seconds with her would have been excellent . . . but if you were trying for 45 minutes, and there's nothing else you can do, that parent needs to have the right to walk in there before the child completely goes. . . . {weeping}

Missing the opportunity to be with the child during the last moments of life was described as detrimental by several study parents and resulted in regrets and negative memories of the experience. Parents (64%) expressed regret in not holding their child prior to death or not being present at the actual time of death.

Parents who were able to participate in the care of their child prior to the death described this period as helpful to them in preparing for the impending death. Other parents reported looking back on this period with regret for not having done more with their child prior to death.

#### Theme 4: Supporting Families With Designated Physical Space for Death to Occur

Parents described the setting and environment where their children's death occurred as influential in coping with, as well as remembering, the event. Saying goodbye to a dying child and completing tasks described as important prior to death were impacted by the physical place where dying and death occurred. In addition, having staff trained in end-of-life care in such a setting was also stated to be important.

One parent whose infant died in the NICU described how the setting was conducive to

mourning at the time of her infant's death. The NICU has a room setup (a bedroom with a bathroom, rocking chairs, and a telephone) and was decorated as a home would be. This room has dual functionality as it is used both for rooming-in for parents taking home an infant with complex medical needs and for infants who are in the dying process.

Another parent who did not have access to this room and whose child died in the same unit described needing privacy as well as separate space:

I know we were making a lot of noise, and sobbing pretty loudly. So at that point you know that you can't do this forever, but you don't know how to grieve. . . . From that point I think that you can't describe how awkward it is, but eventually they have to move you out and get you into the small room right there at the NICU. They had us go in there for awhile with Anna, so, to make phone calls, say our good-byes, and all that good stuff.

Eight of the parents interviewed experienced the death of their child in the PICU. Unlike the NICU, the PICU has no designated room for dying children. The rooms are standard intensive care rooms surrounding the main workspace area. A parent who had a child die in the PICU expressed the following:

It's too, too sterile. I mean it was the same shiny floor with the same chair, and nowhere for me to really sit to be comfortable with him. Maybe like, uh, something with a couch or something that other family members could be invited into.

When asked for suggestions on what would have been the preferred environment, several parents described a "hospice" room:

Something. . . that's more comforting, a place of dying would be a much better setting. A nice view, a nice room, and then the whole family can be in there because this is a child who is not going to continue to breathe. He's going to let go of life.

Many of the parents had not had prior experience with the death of a loved one. The description of a coach or the use of the word *coach* was a common theme in the interviews. The need to have a health care professional who is trained in end-of-life care—someone to describe in detail what the death experience was going to be like, look like, and feel like—was expressed by parents. Having such a coach was described as both desired and helpful. According to parent report, staff members who were knowledgeable and competent in end-of-life care were an asset to parents, as many of these parents felt that they were uncertain of what was

happening and were unsure what steps they should take to prepare for the events leading up to and immediately following the death of their child. Competent staff guided parents during the process. Some parents felt that the staff was uncomfortable with a dying child and left the parents feeling abandoned and left to cope on their own. Parents reported no particular area of the hospital where the staff was consistently trained or competent in end-of-life care.

One parent stated, “it is the responsibility of the nursing staff to tell us what is about to occur so that we can be prepared.” For those who described having such a coach or a guide, be it a health care professional or a family friend who had experience with the death of a loved one, the experience was described as less frightening. The following example illustrates how a coach was of benefit:

And she was the one who came in and she prepared me. She said, “This is what you’re going to do. This isn’t going to be easy; it’s going to be really hard. You’ve got this one step to go. You’re going to hold him and then they are going to disconnect him from the machine . . . and depending on him, he’ll either stop breathing . . . he may breathe for a few minutes and then he’ll stop breathing.” And it was just like she said . . . that was exactly what happened.

Parents described simply not knowing how to grieve or what steps to take during the dying process and, ultimately, the death of their child. Not participating in their child’s care, not being present at the child’s actual time of death, and not asking more questions regarding their child’s status were described as factors that led to parental regret after their child had died.

### Theme 5: Impact of Policy, Procedures, Process, and Rules

Parents described the routine practices in the hospital setting, such as following policy and procedures or issues of process, as detrimental to mourning during the time of their child’s hospitalization. Many of the parents had difficulty with routine procedures and rules during their child’s hospitalization. Of this group, most stated that, although institutional rules might be appropriate in many instances, such rules should be relaxed when a child is dying. On the occasion when staff made exceptions to certain rules, parents felt grateful.

Some parents described not having bathroom facilities in their child’s room as problematic. They would opt to simply not use the bathroom for

personal hygiene or would postpone bathroom breaks as long as they could so as not to leave their child. One parent described not wanting to leave her child under any circumstance, as she feared not being present if he died. Rather than eating in the hospital room, she was asked to leave to eat. She described why this was problematic:

I think it’s nice that you can go visit later in the night if someone gets sick. They’re more open to that. That’s good. But don’t ask me to leave my son, who I wouldn’t leave to go to the bathroom, to go eat because you’re not allowed to bring food in the room, it’s not hurting anyone, as long as it’s not hurting any of the other kids.

Three of 11 parents described receiving a bereavement package at the time of their child’s death and recommended that this be a standard process for parents facing the death of a child while hospitalized. Two parents described how important this was and how they cherish the items today. One parent brought to the interview the items given to her at the time of her child’s death. The following comment is from a parent who was given a remembrance box of her child’s belongings before leaving the hospital following her child’s death:

We got a little special pillowcase that somebody had made to carry his belongings out with. It was wonderful. We got a little box with a ribbon and we put a lock of his hair in that. And she cut all his bracelets off and we put that in a bag, they have a special little bag they give you. So all of those things are just very near, just very near and dear to my heart.

One parent suggested that the hospital have an information packet available to parents that would help them with the process of burial for their child. Knowing what to expect, who to call for burial information and services, what costs to expect, and how to make funeral plans was described as very important and something that was not available when her son died. Another parent suggested that grief counseling, particularly for siblings, would also be helpful.

### Theme 6: Role of Anticipatory Mourning and Its Relationship With Bereavement

Seven of 11 parents interviewed expressed that they knew their child was dying and had begun to mourn the loss prior to the actual time of their child’s death. Parents stated that if they had begun the tasks associated with preparing for the death of their child, their bereavement would have been positively impacted. Parents expressed that assist-

ing in the care of their child, performing rituals, holding their child, being afforded separate physical space, and having time to grieve facilitated bereavement following the death of their child. Of those who expressed awareness, all felt that having this knowledge was helpful as it afforded time to complete the tasks they deemed important during the hospitalization period.

Parents who reported not being aware of their child's imminent death stated that they felt unprepared for the event and for the processes and rituals they might have participated in or completed prior to the death of their child. This was described both in instances where the child had a progressive terminal illness and in instances when the child had been previously healthy. Two parents stated that nothing could have prepared a person for the death of a child.

The majority of parents stated that bereavement could be positively impacted or influenced when anticipatory mourning occurred. One parent, who knew that his wife's pregnancy was high-risk and thus was cognizant that their unborn children could potentially die prematurely, illustrates this:

Yes, [I think anticipatory mourning facilitates bereavement], umm, I think so. I think it would have. We lived through, went through that whole pregnancy thinking that we could lose them [triplets] at any time, so I think that if it had happened, we would still be grieving, but I think it would have been a little different, in that we certainly had to prepare ourselves....

### LIMITATIONS

There were several limitations of this study. Although study subjects were identified and selected based upon the location and the time of death in an attempt to avoid selection bias, all parents who consented to the interviews were Caucasian. Culture and racial background may influence the perception of the experiences surrounding the death of one's child, but it was not determined by this study.

Two of 11 caregivers interviewed were fathers, and the remainder were mothers. This sample size was not large enough to determine the influence of gender or parental role on anticipatory mourning. The two fathers who participated stated that they would not describe themselves as spiritual beings. This characteristic (and its relationship, if any, to study questions) was not examined more in depth due to the small sample size.

The timing of the interval between the occurrence of death and the interview process may also limit the findings. It is unclear how long after the death of a child memories fade or are altered, if at all. It is difficult to ascertain what effect time frame has on recollection of events, particularly the ones that are so emotionally charged.

### DISCUSSION

This study proposed to examine the presence and the process of anticipatory mourning, and to identify practices that are helpful or detrimental to parents who experience the death of a hospitalized child by exploring the lived experience of bereaved parents. Although there is often little intervention that has the potential to change the outcome of a child's illness or disease, the framing of events for a parent experiencing such a loss certainly can.

In administering care to a dying child or in sharing bad news with parents with a child not expected to survive, compassionate, honest, and attentive staff members can tremendously influence the perception of the situation. Families are often unprepared for the death of a child even when the death is expected, such as with progressive illness or disease. The loss of a child is an event for which parents are never prepared (Rando, 1984). Attempting to deal with such an overwhelming situation leaves most parents little reserve for trying to cope with the event without adequate support. The majority of parents interviewed in this study considered themselves novices in terms of exposure to, and experience with, coping with a dying person.

The impact that health care staff can have on parents who sustain the death of a child while hospitalized is significant. The findings in this study are similar to those of Contro, Larson, Scofield, Sourkes, and Cohen (2002), which included families receiving inadequate information and often encountering insensitive health care staff. Parents who sustained the death of a child, as also described in the Contro et al. study, described health care professionals as having a profound impact on how the death was experienced. Families who received explanations of treatment goals, with attention to their understanding of and preparation for the events that were unfolding, were also described as helpful in a recent study of Mack and Wolfe (2006). The presentation of paperwork for legal or hospital policy, such as consent for

autopsy, should be handled in as sensitive a manner as possible, with a focus on appropriate timing, according to parents interviewed in this study. Parents described needing time to grieve and found the presentation of autopsy consent forms an intrusion to their active grieving at the time of, or shortly following, the pronouncement of death. Additionally, parents stated that the consent for autopsy should be presented in such a way that parents understand the purpose and meaning of such.

How these parents perceived the experience at the time of death or in the following period positively or negatively influenced their bereavement period and memories of the event. This was also demonstrated in studies performed by Macdonald et al. (2005) and Miles (1984). Parents have a need to find meaning during the period leading up to their child's death.

How bereavement affects the recollection of events is not clearly understood. Those who experience bereavement appear to be influenced by numerous factors and events, only one of which is the anticipatory mourning experience.

Several themes from these interviews provide insight into what may be beneficial in assisting parents during the time frame leading up to, and including the time of, their children's death. The first of these is the theme of desiring information, particularly detailed information, that would serve to assist parents in their attempts to grasp and understand the events that are occurring. Providing information helps the parents begin to process what is occurring and to attempt to come to terms with not only the present situation but also with what lies ahead. Without this information, parents cannot be expected to make informed decisions regarding care for their children.

The need for a health care member to function in the role of coach, who can assist, describe, and guide parents through what is involved and anticipated in the dying process, is a strong theme expressed by many parents. Parents interviewed in this study did not want to be alone, but rather expressed a need and a desire to be guided through the dying process of their children.

Being physically present and participating in the care of the child leading up to and following the death were desired and considered important for study parents. Final acts of parenting are beneficial to enable and to empower parents to feel that they had done everything possible in caring for their children through the dying and death process. Such parenting behaviors should not be withheld simply

because a child is dying. Allowing parents to participate in their child's care, however simple the task, may provide a sense of control in what certainly must be a situation that seems out of control from a parent's perspective.

The actual setting where death occurs appeared to influence the perception and experience of parents in this study. There is a need to be in a comfortable soothing environment where there is freedom to grieve and to complete tasks deemed important to be performed by parents as their child was dying. Ideally, this environment would be a room away from the activity of the hospital ward, particularly the intensive care setting.

### IMPLICATIONS FOR PRACTICE

Holistic programs for serving dying children and their families while allowing for specific cultural and individual needs as situations arise can be designed and implemented. Providing a system in which the family becomes the focal point of the dying process, not merely the dying child, may facilitate anticipatory mourning. Programmatic design should focus on providing services that are holistic, family-centered, and available to parents across all inpatient settings. Through the creation of intentionally designated physical space, with décor and function similar to those found in a birthing room, anticipatory mourning can be enhanced. The mere presence of such designated space may heighten awareness among staff that these children and their families have unique needs—needs that require staff with expertise in end-of-life care in an environment that is conducive for families preparing for the death of their child.

The emergence of pediatric palliative care programs reflects the recognition of the need to improve the manner of caring for sick and often dying children by health care professionals and institutions. With such programs in place, be they designated physical space, staff trained in end-of-life care, bereavement teams, or palliative care teams, children and families have access to staff trained in end-of-life care within institutions that accept, embrace, and promote the philosophy that dying well is indeed "doing something." Creating a culture that is supportive of health care staff delivering expert care, as well as supporting families in this most important time, is key to improving end-of-life care for children and those who survive their death.

## CONCLUSION

Families want and deserve care that is in concert with their culture, belief systems, parenting styles, and individual preferences when their child is dying. Providing a system where the family unit, not merely the dying child, is the focal point of the dying process can facilitate such an experience. Having staff members who are comfortable with and competent in end-of-life care and who can assist parents throughout the dying process of a child is equally important and necessary as having staff trained in providing life-saving care.

Children will die. The impact of their deaths will continue to be devastating for parents and families. Recognizing the presence of and facilitating anticipatory mourning is one way to positively influence

the experience, and hence bereavement period, for parents who have a child die. By positively influencing the experience surrounding the death of a child, memories of the death experience can be recalled in a favorable manner, in spite of the devastation created by the loss of a child.

## ACKNOWLEDGMENTS

To those parents who agreed to participate in this study in spite of their profound loss, please know that, by sharing your experiences, you have inspired change and have enabled those following in your footsteps access to improved palliative and end-of-life care services for children and those who love them. Your voices continue to be heard, far beyond the written word.

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