Current Approaches to Helping Children Cope with a Parent’s Terminal Illness

Grace H. Christ, MSW, DSW; Adolph E. Christ, MD, DMS

ABSTRACT Much has been learned about childhood bereavement in the last few decades as studies have increasingly focused on the direct interviewing of children about their recovery from the tragic loss of a parent. It has been shown that children do indeed mourn, although differently from adults. Important moderating and mediating variables have been identified that impact their recovery from the loss of a parent, which can be the focus of intervention. When death is expected, the terminal phase of an illness has been found to be particularly stressful for children, yet seldom investigated. Similarly, few studies have explored the impact of development on children's experience and expression of grief. We present research findings that clarify phases in children’s experience during the terminal illness, hospital visits, the death, and its immediate aftermath, as well as how the parent is mourned and issues in longer term reconstitution. Variations in children’s responses in these phases are described as they were experienced by 87 children from 3 different developmental groupings: 3 to 5 years, 6 to 8 years, and 9 to 11 years. Recommendations are suggested for parents and professionals about ways to understand and support children during the terminal illness, at the time of death, and during the phase of reconstitution. (CA Cancer J Clin 2006;56:197–212.) © American Cancer Society, Inc., 2006.

INTRODUCTION

For a child, the death of a parent is a highly stressful event. Research suggests that it places them at risk for adverse psychosocial consequences. However, with adequate family resources, competent substitute care, and emotional support, bereaved children are better able to return to previous levels of functioning.1–4 When death can be anticipated, as with a terminal illness, physicians and other health care professionals have an opportunity to ameliorate the impact of the loss. The experiences of adolescents who confront parent loss from illness and the ways professionals can support their coping were reviewed in an earlier article.5 Presented here is an update on current approaches to helping children (age 3 to 5, 6 to 8, and 9 to 11) cope with a parent’s terminal cancer illness and death. These approaches are informed by three areas of research:

• Risk and protective factors that mediate the coping of bereaved children.
• Intervention during the terminal illness.
• Developmental grouping of children to enhance specificity and accuracy of findings and interventions.

Suggested are ways to better prepare families and health care professionals to facilitate children’s mastery of adaptive tasks during the terminal phase of the parent’s illness, at the death, and during its immediate aftermath.

1This work was supported in part by grants from the National Institute of Mental Health (NIMH) (MH41967), the American Cancer Society (PRB-24A), the van Ameringen Foundation, the Society of Memorial Sloan-Kettering Cancer Center, and the Project on Death in America of the Open Society Institute.
Early research in childhood bereavement hypothesized links between unresolved childhood grief and subsequent adult psychopathology.\textsuperscript{6–8} While early studies appeared to establish a link,\textsuperscript{9,10} later research was able to control for independent, moderating, and mediating variables associated with outcomes that suggested child bereavement alone was unlikely to be related to adult psychopathology.\textsuperscript{11} Rather, these studies highlighted the importance of mediating and moderating factors associated with bereavement, such as the quality of parental care and the presence of other adverse social and psychological occurrences preceding and following the bereavement that may have more influence on adult outcomes than the fact of the death.\textsuperscript{12}

Studies conducted shortly after parent death, including interviews with children, have confirmed that children do indeed experience grief, sadness, and despair following the death of a parent. As Dowdney states in her review of child bereavement research, “Inconsistencies in the literature relate to rates of disorder or disturbance rather than to the manner in which children manifest distress.”\textsuperscript{8} The highest rates of psychological symptoms are found in samples that include children referred for bereavement services or those from less stable backgrounds or under-resourced family environments.\textsuperscript{8,13,14} In adequately resourced and stable family situations, those with clinical level symptoms extending beyond 1 year after the death of a parent are about 20%. For example, Lin reported that 40% of bereaved children had clinical symptom levels in a sample of children whose families were seeking bereavement services and who were subsequently entered into a parent-child skills training program.\textsuperscript{4} By contrast, the Harvard Bereavement Study reported only 19% of their publicly recruited sample of bereaved children had clinical symptom levels on the same measure at approximately the same time since the parent’s death.\textsuperscript{13} These studies do not include longer-term outcomes. One study reported an elevation of symptoms 2 years after the parent’s death, suggesting the possibility of later consequences.\textsuperscript{13}

Recent studies have also identified a broad range of risk and protective factors that continue to be explored, refined, and utilized in developing interventions and service programs. Those currently under study are summarized in Table 1. Prospective and retrospective studies confirm the critical role of the surviving parent or caregiver in helping children adapt to a parent’s death. The quality of the relationship with the surviving parent or caregiver and their competence in parenting bereaved children are the most consistently identified mediating variables.\textsuperscript{3,15–20} Caregiver attributes that contribute to children’s adaptation include more active coping, less depression, more parental warmth, and family cohesiveness.\textsuperscript{4,20} While the connection between children’s mourning experience and adaptation level has not been clearly documented, better psychological outcomes have been associated with broader characteristics, including openness of general communication with the surviving parent and sharing of information about the parent’s death.\textsuperscript{21,22} Parents often find it difficult to understand and respond to their children’s unique, developmentally specific expressions of grief, which may seem vague, intermittent, and at times inappropriate by adult standards. Adults find that children can even appear to be unconcerned, callous, or indifferent.

Helping Children Cope during the Parent’s Terminal Illness

The surviving parent’s management of the terminal illness experience and preparation of their children for the death are viewed in the clinical literature as important mediators of children’s bereavement, yet there has been little investigation of the children’s coping during this time period. Siegel reports that children (age 7 to 17) whose parents were in the terminal stages of illness displayed significantly higher levels of depression and anxiety than community controls.\textsuperscript{23} At follow up, between 7 and 12 months after parental death, differences between the groups had become nonsignificant.\textsuperscript{3} These findings suggest that when parental death follows a lengthy terminal illness, child disturbance may precede the death.
itself. Indeed, for children it may be the time of highest distress. Other recent retrospective studies of bereaved children continue to document misunderstandings and guilt surrounding the parent’s deteriorating condition and terminal illness.24,25 These studies also reported bereaved children’s memories of anxiety and disappointment when visiting and interacting with the ill parent, memories that remained painful and disturbing during the first years after the death.

Few interventions have been developed to address these stresses and parenting challenges. Only one intervention studied focused on helping surviving parents achieve effective communication with their children about the patient’s impending death, including mediating successful visits when the patient was in the hospital.26 Newer medical treatments have extended the terminal illness period for many cancer patients so that it may now include periods of disease exacerbation and aggressive treatment, alternating with periods of reduced symptoms and disease control when life can proceed more normally. This gives families much needed hope, but also creates new adaptive challenges. Determining prognosis, that is, when death is imminent is increasingly difficult.27 Both parents and physicians must find new ways to communicate about the illness, explaining what children see and hear and preparing them for difficult times, but also reassuring them of the parent’s well-being when their condition is stable or has improved and encouraging adaptive denial to permit quality time together while symptoms are reduced.

Many parents strive to limit the adverse impact of the loss on their children’s future development and frequently request guidance from physicians about how best to communicate with their children during the parent’s terminal illness.3,24,28,29 Children and adolescents report that they value open communication with both parents about the illness and death, and research suggests that it helps them during their bereavement.21,26 Younger children are less likely than adolescents to receive information about their parent’s terminal condition before the death.22 This is thought to occur because young children have less access to adult information, their more limited cognitive abilities make it difficult to explain the situation to them, and adults, often incorrectly, believe they are protecting them from the emotional pain of loss by not discussing it with them ahead of time. As a consequence, children’s particular questions and needs during their parent’s terminal illness are less understood.

**Age-specific Information**

When death is imminent, physicians and other health professionals can help prepare parents by providing specific, concrete information and practical advice to facilitate coping and meeting children’s needs at this very stressful time in the family’s life. Unfortunately, re-

---

**TABLE 1 Risk Factors Impeding and Protective Factors Promoting Reconstitution**

| Risk Factors Impeding Reconstitution |
|-------------------------------------|
| Concurrent stressful life events    |
| A negative or non-supportive relationship with the surviving caregiver |
| A poor relationship with the parent who died |
| Low self-esteem and an external locus of control |
| Preexisting mental health problems in the adolescent or the surviving parent or caregiver |
| Circumstances of the death, such as violent or traumatic death |

| Protective Factors Promoting Reconstitution |
|--------------------------------------------|
| Having a relationship with surviving parent or caregiver characterized by open communication, warmth, and positive experiences |
| Surviving parent able to sustain parenting competence |
| Feeling accepted by peers and other adults, such as relatives and teachers |
| Higher socioeconomic status |
| Internal locus of control, religiousness |
| Intellectual and social competence |
| The opportunity to express thoughts and feelings about the deceased parent and have them validated by others |
search on developmentally specific responses, although requested by parents, has been limited. While clinical case studies have reported different cognitive and emotional responses of preschoolers, school-age children, and adolescents, no differences in disturbance by age have been established. A study of bereaved 3- to 5-year-old children found that, contrary to the guilt generally described in older children’s grief, children this age experienced no feelings of causal responsibility. Rather they are reported to show separation anxiety, dependency, nighttime fears, regressive behaviors, irritability, and impatience. Another age-specific study focused on bereaved adolescents. Adolescents younger than 15 years old at the time of the parent’s death were found to be more vulnerable to depression than those 15 to 19 years of age. Other clinical literature has attempted to clarify the grief process during adolescence, but the specific effects of parental death on the mental health of this age group have remained largely unexplored.

**NEW DIRECTIONS**

Three National Institute of Mental Health (NIMH)-supported studies addressed child bereavement issues using prospective rather than retrospective designs. Two programs studied families following the death of a parent to provide generalizable information about the response and recovery processes of expected and unexpected deaths, including those from accident, suicide, and homicide. Worden’s Harvard Child Bereavement Study yielded important insights about the recovery processes reviewed above. Children and adolescents were more symptomatic at the second than after the first anniversary of the parent’s death. Sandler provided a carefully controlled parent and child skills training intervention. Families were recruited from those seeking preventive bereavement services, and these distressed families improved following a series of 12 group sessions.

The Memorial Sloan-Kettering Cancer Center study (MSKCC) compared 2 interventions (a parent-guidance and a telephone supportive intervention) conducted with families beginning 3 to 6 months before the patient died and continuing for 14 months after death from cancer. Families with children who had a serious preexisting emotional problem were excluded. This more homogeneous population made it possible to group children with similar cognitive, emotional, and sociocultural developmental attributes. As presented below, this grouping clarified clinically important differences in their responses to the illness and death of a parent. The exclusion of unpredictable deaths also made it possible to understand the impact of the highly stressful reactions to the terminal illness and the value of providing interventions during this critical stage.

A qualitative analysis was used with the intervention interviews of 157 children from 88 families. Five different developmental groupings were identified: 3 to 5 years, 6 to 8 years, 9 to 11 years, 12 to 14 years, and 15 to 17 years. Other clinical literature has attempted to clarify the grief process during adolescence, but the specific effects of parental death on the mental health of this age group have remained largely unexplored.

**DEVELOPMENTAL VARIATIONS IN CHILDREN’S RESPONSES TO A PARENT’S TERMINAL ILLNESS**

**Sample**

The sample in the MSKCC study included both children and adolescents. The findings presented here were drawn from the 87 3- to 11-year-old children whose families participated in the parent-guidance intervention. There were 11 girls and 7 boys in the 3- to
5-year-old group; 16 girls and 16 boys in the 6- to 8-year-old group, and 18 girls and 19 boys in the 9- to 11-year-old group.

**THREE- TO FIVE-YEAR-OLD CHILDREN: “WHERE DID HE GO?”**

**Key Developmental Characteristics**

- Early preoperational thinking makes it difficult for them to understand the meaning of the illness and the permanence of death.
- They can repeat a memorized script that explains the situation, but without understanding it.
- Communication is mostly through play and fantasy.
- Limited language skills make it hard for caregivers to comprehend young children’s behaviors and moods.
- Their world consists almost exclusively of family centered around the home and their relationship to the primary caregiver(s).
- Separation from a primary caregiver is their greatest source of stress. Even very young children can experience night terrors and other more obvious distress responses related to the sudden and frequent removal of a primary caregiver.
- Fortunately, children this age can accept competent substitute caregivers, especially if prepared for the possibility of unexpected substitutions.
- Young children can become distressed by the primary caregiver’s outbursts of grief, their inability to mute or filter strong reactions, or their emotional withdrawal from illness or exhaustion.

**Intervention during the Parent’s Terminal Illness**

Three- to five-year-old children can observe the parent’s loss of strength and function, such as the inability to lift them. “Daddy can’t take care of me anymore,” said a 3-year-old who observed her father’s difficulty with ambulation. They begin to understand that something is wrong, but cannot comprehend the permanence of death. If the parent discusses it with them, they might say the words, but with limited understanding. Nevertheless, it is often helpful for parents to give children a script, an explanation of events that they more fully grasp as they mature.

A 7-year-old said of her 4-year-old sister, “Before my mother died, my sister wanted to talk about her death, because she thought it was like an exciting thing. She thought she would come back. Now she’s mad because she didn’t come back.”

Another 7-year-old described her 4-year-old sister’s reaction: “The night Daddy died, she and Mummy came to my bed. Mummy said, ‘Your father died,’ and my sister was laughing because she thought something exciting had happened. She didn’t know what dead means. It was very sad; Mummy cried until the priest came, then my sister cried too.” The mother added, “She cried because I cried.”

During a father’s terminal illness, one 4-year-old expressed her anxiety about his obvious frailty by describing her new imaginary companions, brothers and sisters who became ill and died and were immediately replaced with new “bigger and stronger brothers” who watched over her and took care of her. This play lasted several weeks and was gradually elaborated as her father’s illness progressed. It seemed to reflect her anxiety about his symptoms, the well parent’s distress, and her belief and wish that the father would return and be able to take care of her again.

It is important with children this age to locate a competent substitute caregiver when necessary and repetitively reassure children that they are loved and will be taken care of.

**Planning Hospital Visits**

Some parents misunderstand “open communication” to mean the full expression of their intense grief with young children. One 3-year-old developed a fear of entering her father’s hospital room because her young parents tended to cry together when she was there. The mother was referred to a social worker who helped her structure the visits, control her strong emotions, limit the time of the visits, and bring things for the daughter to do with her father. The child’s fears decreased and the
visits were often pleasurable. If the parent is in the hospital for an extended period of time, young children can be relieved to see them, however briefly.

At times, parents resist having their young child see them in a debilitated state. If the parent, child, and hospital staff were prepared, the visit structured, and the patient’s condition explained by staff, the visit was positive, and the patient was not remembered in a negative way. Children generally develop positive memories and images of the parent shortly after the death. At times a parent resists contact when in a debilitated state because they do not want to risk infection by handling a child or they have no energy to cope with a child’s emotion and developmentally appropriate physical demands. These situations must be explained to children to counter their feeling that they are being rejected because they are bad. The patient’s vulnerability must also be respected. Alternative modes of communication (eg, telephone, note cards, or gifts) can be helpful.

The Death and Its Immediate Aftermath

When death occurs, children in this age range require concrete descriptions of what happens to people when they die—loss of functions, permanence of the death, as well as sadness and other emotions people feel after the death. When told of the parent’s death, children this age are often befuddled, wondering where the parent has gone. Repetitive questioning about where the parent has gone is characteristic for weeks and months after the death. Although such questioning helps children this age develop a sense of mastery, it can evoke overwhelming emotions in the grieving, surviving parent. Having children participate in bereavement play groups or talk with another adult about the parent who died, like aunts or uncles of the deceased parent, especially telling stories about the parent, can provide opportunities to support the child and at the same time relieve the grieving parent. Children this age often enjoy bereavement groups, relevant art therapy, or other expressive sessions after death has occurred. Many children also want to place things in the coffin with the parent (eg, stuffed animals, pillows, pictures of the parent, or toys the child especially likes).

As children this age experience the parent not returning day after day, they may become increasingly angry and distraught over time. Older siblings can become impatient with having to answer their demanding questions.

One 4-year-old girl became whiny and clingy after her father died. Occasionally, she sat in his chair with many blankets wrapped around her. When she began complaining of stomach aches, her mother took her to the doctor, and she promptly asked him when she could see her father again. Three months later, she was able to say, “Daddy died.”

How the Parent is Remembered

The children’s memories of the deceased parent were generally positive soon after the death, focusing on pleasurable experiences, caretaking, and protective functions. Many loved to hear stories about the deceased parent. One 4-year-old enjoyed when her sister made their father’s favorite pancakes using his “secret” recipe or when they carefully tended Daddy’s garden. Another 4-year-old recalled that his father had tickled him; another talked with pleasure about how his father had tossed him up in the air. Recapturing such experiences seemed to comfort them. However, after some time, most children this age requested that the surviving parent find a replacement. Young children wanted a whole family, like the other children in their preschools had.

One 5-year-old said, “Next time, get two daddies, so if you lose one again.”

The Course of Recovery: Issues in Reconstitution

One mother explained that her 4-year-old son was not mourning. Rather, he seemed very happy because she was now home much more regularly than she had been during his father’s terminal illness. The central focus of children this age on the primary caregiver meant that their consistent and predictable presence was essential. The primary caregiver often needed to function as a “Rosetta Stone,” helping to
interpret the child’s behaviors and affects to others, as well as to the child.

SIX-TO EIGHT-YEAR-OLD CHILDREN: “I THINK I KILLED HER”

Key Developmental Characteristics

- Late preoperational thinking\(^3\) includes both magical and logical thinking.
- Children understand the parent will not return and death is universal (it could happen to me).
- Children may be highly emotional and have difficulty containing emotions.
- They blame themselves when bad things happen.
- They may make logical errors, misunderstanding cause and effect.
- They can show fear that aggressive thoughts, words, or wishes can be harmful.
- “I prayed my mother would be out of pain the night before she died. I think I killed her,” said a 7-year-old girl.
- They cannot retrace thinking to origins of error to correct erroneous ideas.
- Parental support of self-esteem is still needed, but now they are also aided by praise of teachers.
- Although parents are a primary source of self-esteem, they fear rejection by peers.
- A 7-year-old girl cried because a classmate said, “You can’t go to the father-daughter dance because your daddy is dead!”
- Language skills are more advanced.

Intervention during the Parent’s Terminal Illness

Three types of information are helpful to 6- to 8-year-old children during the parent’s terminal illness: (1) simple, concrete, definitional, disease-related information, such as the name of the disease, its progress, symptoms, treatments and causes; (2) simple explanation of the causal relationship between the patient’s behavior and appearance and the symptoms and treatment of the disease; and (3) when death is imminent, the prognosis. These children may well overhear conversations that include this information. One 8-year-old boy developed elaborate eavesdropping methods, picking up extension phones, and listening through closet walls. However, we observed that if parents spoke candidly and explained major changes directly, children then felt free to ask questions, and misunderstandings could be clarified.

In this age range, children’s awareness of their parent’s death can be quite varied. Many spoke openly about being afraid their parent would die, even when their parents had previously told clinicians they thought their children “had no idea” about the parent’s diagnosis and did not understand about their imminent death. Other children, though aware of the illness, were unaware of the terminal nature of the current episode. A few were unclear about the diagnosis and therefore were confused about what was happening to the parent. Most had “anticipatory anxiety” rather than anticipatory grief as experienced by adolescents and adults. They sensed something “catastrophic” was going to happen, and they wondered if they or their family would survive it.

An 8-year-old boy whose father was terminally ill said, “I began to think maybe Grandma and Grandpa would die, my mom would also die, and maybe the whole world would end, and nothing would be there.”

These children tend to be highly emotional and reactive to the many changes taking place in the family as a consequence of the parent’s illness. Indeed, this seems the most difficult age for parents to manage during the predeath period, even though existing research has not necessarily identified them to be at higher risk over the long term. They are upset by both parents’ preoccupation with the ill patient’s condition and their difficulty in listening to the child or playing with them. They react to separations and to changes in their own activities. They react to the parents’ increased tension, anger, and depression, and to the lack of happiness, joy, and celebrations in the home. Explanation of what is happening, even if the child does not ask, is often helpful and can give permission for the child to ask more questions.

Children this age find it difficult to “reverse” their thinking once they develop an erroneous idea. Therefore, even when parents explain the patient’s withdrawal is not from a lack of love.
and that the illness causes these changes, they may remain angry and upset for some time and require much repetition. These children are also “truth tellers” or “whistle blowers” and will readily express emotions and situations their older siblings have learned to hide or disguise.

One 7-year-old girl whose father was terminally ill with a brain tumor described the changes in their family. “Mom and Dad used to go dancing. They don’t do that any more, and Mom is angry all the time. Dad won’t let me sit on his lap. I don’t think he loves me anymore.”

Parents often find it useful to enlist the help of other adults or professionals to listen to their children’s distress. The parent’s own emotional state as the patient’s death approaches or in the postdeath period may limit their capacity to attend in a helpful way.

**Planning Hospital Visits**

Although the 6- to 8-year-olds do not need the parent’s constant presence, as do 3- to 5-year-olds, they do need the parent to be as consistent as possible with them. For example, this includes letting them know about the possibility of emergency trips to the hospital and preparing them for how the situation will be handled and who will take care of them when both parents are absent. If separations are not prolonged, and they are aware of the parents’ whereabouts, they can be tolerant of temporary caregivers and babysitters. However, if separations are prolonged, they become distressed, especially if they are not permitted to visit the parent in the hospital. In these situations, a planned visit can reduce their anxiety dramatically and lead to improved behavior at home. Some patients want to protect their children from their altered appearance. However, we found that most children this age spoke only briefly after the death about the sick parent’s appearance. They were more likely to feel rejected by the parent’s not wanting to have them visit.

Six- and four-year-old brothers were reported to be fighting more than usual even though they had a housekeeper during the day while their mother was in the hospital. When the clinician asked how they were feeling about their mother being in the hospital, they responded angrily that she had been there for 62 days. They knew that because they had been crossing off the days on a calendar they brought with them. Their behavior improved markedly after the brief visit with their mother.

As with younger children, preparation for the visit is essential. When the patient’s condition and physical state, intravenous bottle, etc., can be explained, the interaction with children is facilitated. Discussion afterward is easier and can more readily clarify any misunderstanding. If parents cannot cope with visits, they can help children by telephone communication and exchange of letters, drawings, and gifts. However, seeing and hearing the patient and his or her caregivers in the hospital not only provide the child with an important confrontation with reality, but also with reassurance that is difficult to achieve in other ways.

**Saying Good-bye**

It was unusual for patients to talk with their children this age about their own imminent death. When an ill parent did so, the child often reminisced with pleasure about having said final good-byes to the patient. However, as others have suggested, saying the word good-bye seemed not as important as a final hug, squeeze of the arm, and repeated affirmation of love.

A 6-year-old said, “I wanted to hear those magic words, ‘I love you.’”

An 8-year-old remembered his father saying, “I love you,” to him.

One 7-year-old remembered how she had hugged her mother.

Another 7-year-old was comforted by remembering that, even though her mother could not talk any more, she had squeezed her hand. For months, she put herself to sleep with this tactile memory.

If children did not say good-bye to the patient directly, they were often comforted by writing their thoughts down and placing them in the coffin. The mother of one 8-year-old boy placed his letter in her husband’s hand in the casket.
The Death and Its Immediate Aftermath

In contrast to their younger peers, children this age generally understand the finality of the parent’s death after an illness and are appropriately sad and upset when informed. Many parents say telling their young children about the parent’s death was the most difficult task they had ever faced. These children express sadness, anger, and dejection connected with thoughts about the parent, but then often quickly return to normative activities. Even when they were well prepared, some expressed surprise and acute distress. They have more physical symptoms than older children, as well as fearfulness, sleeping problems, and separation anxiety. Children this age more than any other might speak openly and explicitly about wanting to die so they can be with or visit the parent soon after the death. Generally, these are transient thoughts and not accompanied by suicidal intent or plans. If they persist or became rigid and inflexible, a professional evaluation is recommended. Their mourning is also frequently expressed by joyous memories of the deceased parent, which is disconcerting to surviving spouses unless they understand that this is an adaptive way to retain a connection to the parent who died. The children spoke openly about talking with the parent who died, and for most, these were comforting experiences.

A 7-year-old girl told her father, “I’m going to pray for Mommy tonight when I give the blessing. Are you going to be sad?” When he said he would be, she brought a large box of tissues to the table and told him, “You always feel better after you cry.”

How the Parent is Mourned

Whatever their religion, children this age tend to locate the parent who died in a place (usually heaven) and often with a function. Most thought the parent watched over them. After receiving coins for her lost tooth, one 7-year-old girl said, “I know where Mom is—she’s the tooth fairy!” Her father affirmed that he thought her mother would love that job.

The image retained of the parent is that of the loving caregiver, provider of good things, and strong, much admired hero or heroine. Active, open, and vocal construction of this image seems to comfort them even though such openness continues to be difficult for their grieving parent. Like their younger peers, they also request a replacement parent, less ambivalently if the parent who died was the same gender as the child. They love talking about and recalling pleasant episodes they had with the parent who died, surrounding themselves with their pictures, and incorporating the parent’s clothing or other objects into their play.

After a long parent illness, children this age did express some relief that the parent had died and was no longer suffering. They also felt relief that they had survived what they feared would be a catastrophic event.

One 8-year-old said, “I can talk more about my mom now than I could before she died because the worst has happened and it’s over. I don’t have to worry that I might make something bad happen [by talking about it].”

Course of Recovery: Issues in Reconstitution

As occurred in every age grouping, most of the children returned to their previous levels of functioning in psychological state, relationships with parent and siblings, academic performance and activities, and relationships with teachers and peers by the end of the first year. It is important to note that most of these families had adequate financial resources to afford hiring substitute parenting and, unlike poor or recent immigrant families, had few other family stresses.

Grief with these children is usually sporadic and brief. Immersion in school and playing with friends are common even immediately after the death and should be encouraged. Schools can be very helpful if teachers are notified. Many children were given permission for short visits to school counselors when they felt sad.

A 7-year-old was overjoyed when one of her friends came to the funeral and went to play with her.

Another 6-year-old felt reassured and accepted when classmates gave her a large bowl
of notes and drawings they made for her after her father died.

At home, bedtime is especially hard. Parents were encouraged to spend time each night reading a story and talking about pleasant memories of the parent. Some slept with the parent for weeks or months.

These children reacted more to additional stress or pressure, some with increasing difficulty in separating from their parent when they were going to school, and even more so on Mondays after a weekend at home. Parents sometimes included a love note with lunches or gave permission for the child to call home for a quick chat. Limit setting, temper outbursts, temporary regression like bed wetting, and clinging were common. Parents appreciated advice about handling those behaviors, understanding them as normal, and gradually improving behaviors. Difficulty in concentrating in school and a drop in grades were common, and children needed to be reassured that those problems were understandable and temporary. For most children, misbehavior took place at home, not in school. Parents grudgingly appreciated that as a better alternative.

NINE- TO ELEVEN-YEAR-OLD CHILDREN: THE YOUNG SCIENTIST

Key Developmental Features

- There is a major change in thinking ability (concrete operational)—these children can use logical thinking, understand cause and effect, and retrace memories to reverse and correct erroneous conclusions.
- Unlike early adolescents, they cannot draw inferences from insufficient information. They need detailed, concrete explanations about the parent’s illness and course of treatment to understand and feel a sense of control.
- In contrast to younger children, they are able to use compartmentalization and distraction to avoid strong emotion.
- They may have outbursts of emotion followed by embarrassment and avoidance.
- These children benefit from being able to help with the care of the ill parent; however, they should not be left independently in charge of a seriously ill parent.

Intervention during the Parent’s Terminal Illness

Many children this age showed a need for carefully sequenced information about the parent’s illness, treatment, and impending death. They were able to integrate relatively concrete and detailed information about the illness without becoming overwhelmed and confused. However, they became frustrated and angry if they were not given enough information. They were unable to comprehend the context in the absence of more comprehensive detail.

An 11-year-old boy said, “Last year, Dad went to the hospital, but they didn’t tell me it was cancer. I thought it was not cancer, just a tumor. My mom finally put it straight to me, but I had to go up to her and ask. Now that I know what’s going on, I understand. Dad used to be grouchy, and I didn’t understand. I thought he was mad about something. Now it doesn’t seem that he is mad at me.”

In contrast to younger children, who could become fixated on particular erroneous ideas, children this age were able to reverse their thinking and correct logical errors.

A 9-year-old girl described how she was different from her 6-year-old sister. “She is much younger, and she doesn’t take things as well as me, she doesn’t understand.” She explained that when her parents clarified the fact that she was not responsible for her mother’s illness, she believed them, but her sister was not so sure. “I know it’s not my fault, and I couldn’t have done nothing to prevent it. It wasn’t our fault.”

The importance of incremental information was highlighted by a study of the responses of children this age who lost parents in or had high exposure to the 9/11 World Trade Center attacks. The bereaved children this age were the most symptomatic group of children in citywide school surveys. The total unexpectedness of the event deprived them of their ability to learn incrementally, and they were overwhelmed with the complexity of the event and the enormity of the loss. In contrast, the
children this age whose parents died of cancer and who received continuous small doses of information about the progression of the illness were among the best adjusted of the five developmentally derived subgroups.

Some children in this age group expressed sadness about the parent’s expected death rather than only the anxiety experienced by younger children. They were the first group to consistently anticipate the death and feel sad about the future loss.

After a mother told her 10-year-old boy that his father’s current treatment was ineffective, he wanted to look at photographs of his father as he had been before the illness. He said he thought about his father a lot and worried about him. He also wondered, “Who will play basketball with me? Who will fix my bike?” He thought he would want to be with his father when he died.

Many children had difficulty in school during the terminal illness, but some children in this age group were able to improve their performance, sometimes as a gift to the ill parent. It was also not unusual for these children to offer to help out with taking care of the sick parent.

A 10-year-old boy volunteered to sleep in the den with his father, waking up every 3 or 4 hours to give him medication. He said he liked to help.

An 11-year-old girl became so expert at helping to transverse her father from the bed to a wheelchair or stretcher that she instructed the ambulance workers how to best do it when they came to take him to the hospital. Her father was very proud of her special competence.

However, parents are cautioned about the importance of not leaving a child of this age placed independently in charge of the care of a terminally ill parent. Unfortunately, where financial resources are inadequate, this does occur. It places a heavy burden on the child with commonly symptomatic outcomes and complicated bereavement if prolonged or when mistakes are made and the parent then dies.

Planning Hospital Visits

Children this age were more distressed than younger children by the parent’s changing appearance and ability to function, the reduction in family activities and trips, and the prospect of a future without the parent’s assistance, support, and love. They experienced some separation anxiety when the patient was in the hospital a long time and the well parent spent a great deal of time there as well. Hospital visits seemed helpful, especially when they included contact with medical and nursing staff who could explain the care and treatment their parent was receiving. They even seemed to benefit from walking around the hospital and becoming familiar with the patient’s environment. Learning details and facts about the place, the treatment, and the care helped them comprehend the context and achieve some sense of relief and control. However, as with younger children, preparing the patient, parent, and staff for the visit helped to avoid misunderstandings. Careful preparation by the clinicians in the MSKCC study may have prevented the negative results of hospital visits that have been reported in retrospective studies. For example, some children were struggling with a drop in grades when their parent was hospitalized, and they feared their sick parent was disappointed in their performance. The parent needed to understand that it was normal to have declines in grades at this time, an expected consequence of the love and worry of their child, and that it was important to praise their efforts during the difficulties of parent illness. Children also valued the exchange of gifts and cards. Children this age seemed to find final visits meaningful even when little communication was possible. They provided concrete evidence of the reality that the patient was dying and gave them an opportunity for final interaction.

The Death and Its Immediate Aftermath

It was viewed as optimal when a child said on hearing of the parent’s death, “I was surprised, but I knew it [the death] was going to happen because my mother kept me informed.” Still, managing intense emotions for children this age was difficult. Some had unusually strong reactions, which they later disavowed.
One 11-year-old boy locked himself in his room when his mother came home from the hospital because he didn’t want to hear the news until he was ready. Later, he was embarrassed about this behavior.

Wanting to be alone for a while was not unusual. Some children cried or screamed. One boy laughed—an expression of acute anxiety. They needed time to collect themselves.

An 11-year-old girl was at school when her mother came to tell her that her father had died after 2 years of struggle with a brain tumor. She asked to be able to remain in school with her friends and to complete a test in her last class. She thought her father would have been proud of her good grades during such a difficult time.

Children this age often avoided their own and others’ strong emotions, especially those related to grief. Participation in bereavement groups or programs could help them to become more open, but often their feelings were expressed in more indirect ways, as by being messy, stubborn, argumentative, or more withdrawn. They tended to control their grief by compartmentalizing—escaping by immersion in school and extracurricular activities. Difficulties with sleeping were ubiquitous; some also developed phobias and fears or a preoccupation with ghosts.

These children treasured clothing and other items that had belonged to the parent. They provided comfort and opportunities to reminisce about the parent, especially during the first year. They enjoyed looking at pictures of their parent in healthier and happier days, but often in more private and less expressive ways than did younger children.

How the Parent is Mourned

Like their younger peers, many children this age left notes and gifts in the coffin with their dead parent that reflected activities they engaged in together—a baseball, a letter. Many listened intently to eulogies and remembered them. Some children this age organized their own memorial services with their peers, giving eulogies or contributing to the eulogies of others. They want to be active participants. These children often thought of the parent who died as watching them when they were succeeding at school or in sports and imagined the parent being pleased with their performance. Rather than focusing only on the parent’s caretaking role, as did their younger peers, they retained an image of the parent as teacher, coach, advocate, and friend. The mother was often remembered as the family organizer, love giver, cheerleader, protector, and someone with whom they could chat. Requesting a replacement parent was quite uncommon in comparison to younger children. If it occurred, it seemed related to more practical needs, such as relieving chores, helping with homework, or sports.

Like their younger siblings, these youngsters also like to hear stories about the deceased parent. The more realistic appraisal of 9- to 11-year-olds is highlighted by humor, as in the following episode:

An 11-year-old boy, his mother, and older siblings were watching the meteor shower shortly after the father’s funeral. The 11-year-old had put two small bottles of his father’s favorite whisky in his casket. Now he pointed out one star that seemed to careen out of control; “That’s Dad up there—he found my bottles of whisky.”

Course of Recovery: Issues in Reconstitution

The course of recovery of 9- to 11-year-old children has much in common with that of their younger and older peers. Unique to this age group are emphases on new developmental capacities: educational, recreational, and social competencies. The stresses of the terminal illness and the death result for many children in temporary depression, anhedonia, preoccupation, and reduction in ability to concentrate. This sequence of responses can affect all domains (educational, recreational, social, and emotional). An important process of reconstitution is the gradual regaining of competence in these areas of great importance to children. The initial explosive outbursts, withdrawal, and anhedonia are of great concern to the surviving parent. They were helped as single parents to set limits, support, and encourage these children, sidestepping the provocative
nature of the angry meltdowns. However, home and parent remained important to the 9- to 11-year-old children. They needed to invest in activities outside the home while still retaining a close bond. They still valued their parent’s love and support. A different dimension of stress and parental trial came from the adolescents who developmentally needed to separate from parent and home.

The 9- to 11-year-olds, 12- to 14-year-olds, and 15- to 17-year-olds spent much more time away from home than younger children. The difference, however, is that the 9- to 11-year olds often moved to activities outside the home, while the 2 adolescent groups moved away from the close parental contact they previously needed and enjoyed.

(2) View communication as a process, not a one-time event. Communicating with children or adolescents about a parent’s terminal condition is best done through careful dosing of information over time, which builds a pathway of open communication and trust that children will be informed in a timely way about major changes in the parent’s functioning or prognosis. The level of detail communicated about the situation is greater with older than younger children. Physicians should encourage parents to provide open and hopeful, but not unrealistic information. Efforts to treat and care for the ill parent are emphasized, but the child must also be assured of their own continued care and love. The resulting dialogue helps children cope with the painful uncertainties that both parents and children must endure in this highly stressful period.

(3) Children and adolescents generally experience emotional reactions intermittently and for brief periods of time interspersed with rapid return to normative functioning. Their capacity for sustained or intense emotion is limited. Sustained, intense grief may reflect symptomatic responses to stress rather than health. Their intermittent grief, as well as positive memories about the parent, have been found to continue to emerge over the course of their development in response to additional stresses or developmental advances.1,43,44

These and the more specific recommendations in Tables 2 and 3 are directed to physicians and other health care professionals treating life-threatening illnesses in patients with children; pediatricians and psychiatrists who may treat children with physical or psychological symptoms of distress; and physicians in palliative care programs and in hospices. Many physicians will not have direct contact with family members other than their adult patients and their spouses. However, integrated into competent end-of-life care is the awareness that the patient is distressed when the family is adversely impacted and that the patient wants the health care team to assist with their family’s needs. Finally the physician’s support and appropriate use of direct services to families provided by other members of the medical team promote effective family-
TABLE 2  Recommended Guidelines for Families during a Parent’s Terminal Illness

| 3- to 5-year-olds |
|-------------------|
| 1. Gradually/consistently explain changes due to cancer and treatment without being overly optimistic/pessimistic. Children can learn “script” of events without fully comprehending meaning and importance; at this age, death is not understood as permanent. |
| 2. Separation from primary caregiver is major concern at this age. |
| 3. Establish consistent time when child can ask questions and share feelings, such as bedtime. |
| 4. Provide consistent substitute caregiving when primary caregiver is unavailable. |
| 5. Use play and art to illustrate and concretize complex events that are occurring in family. |
| 6. Having “a good cry together” may be frightening rather than cathartic for young children. |
| 7. Anticipate child’s increased separation anxiety and need for reassurance that they will be cared for. |
| 8. Normalize intermittent, brief intense emotional expression—changing subject and going off to play are important safety valves. |
| 9. Encourage planned, time-limited visits during prolonged hospitalizations. Assure child has toys, activities to do with ill parent and that parent’s condition, limited capacity is explained. |
| 10. Offer families consultation with social worker or other psychosocial professional for additional concerns. |

| 6- to 8-year-olds |
|-------------------|
| 1. Gradually/consistently explain changes due to cancer and treatment without being overly optimistic/pessimistic. Children can learn “script” of events without fully comprehending meaning and importance; at this age, death is not understood as permanent. |
| 2. Separation from primary caregiver is major concern at this age. |
| 3. Establish consistent time when child can ask questions and share feelings, such as bedtime. |
| 4. Provide consistent substitute caregiving when primary caregiver is unavailable. |
| 5. Use play and art to illustrate and concretize complex events that are occurring in family. |
| 6. Having “a good cry together” may be frightening rather than cathartic for young children. |
| 7. Anticipate child’s increased separation anxiety and need for reassurance that they will be cared for. |
| 8. Normalize intermittent, brief intense emotional expression—changing subject and going off to play are important safety valves. |
| 9. Encourage planned, time-limited visits during prolonged hospitalizations. Assure child has toys, activities to do with ill parent and that parent’s condition, limited capacity is explained. |
| 10. Offer families consultation with social worker or other psychosocial professional for additional concerns. |

| 9- to 11-year-olds |
|-------------------|
| 1. Gradually/consistently explain changes due to cancer and treatment without being overly optimistic/pessimistic. Children can learn “script” of events without fully comprehending meaning and importance; at this age, death is not understood as permanent. |
| 2. Separation from primary caregiver is major concern at this age. |
| 3. Establish consistent time when child can ask questions and share feelings, such as bedtime. |
| 4. Provide consistent substitute caregiving when primary caregiver is unavailable. |
| 5. Use play and art to illustrate and concretize complex events that are occurring in family. |
| 6. Having “a good cry together” may be frightening rather than cathartic for young children. |
| 7. Anticipate child’s increased separation anxiety and need for reassurance that they will be cared for. |
| 8. Normalize intermittent, brief intense emotional expression—changing subject and going off to play are important safety valves. |
| 9. Encourage planned, time-limited visits during prolonged hospitalizations. Assure child has toys, activities to do with ill parent and that parent’s condition, limited capacity is explained. |
| 10. Offer families consultation with social worker or other psychosocial professional for additional concerns. |

centered care. Families have been found to benefit from consultation with a social worker or psychosocial professional during periods of high stress and expected loss.45,46

**Future Directions**

The last decades of the 20th century contributed greatly to knowledge about childhood bereavement, but much remains to be understood about the prevention of later adverse consequences and the enhancement of growth-promoting components after the tragic loss of a young parent.

Three research directions for the 21st century show promise for more specific and less confusing and contradictory findings:

1. Studying developmentally homogeneous subgroups of children and the differing effects of different types of deaths;
2. Conducting longer-term prospective studies that include critical experiences (eg,
TABLE 3  Recommended Guidelines for Families Following a Parent’s Death

| 3- to 5-year-olds |
|-------------------|
| 1. Use concrete details to describe the fact that when a person dies, all bodily functions cease and person does not come back. |
| 2. Use play, drawing, and other expressive activities to enhance the child’s understanding. |
| 3. Normalize emotions children and others might feel so they can respond in ways others will understand. |
| 4. Describe what child can expect to happen, what role child can play, roles other people will play, how others will feel and behave, and how child may feel during funerals and memorials. Encourage participation in these rituals. |
| 5. Assign caretaker able to take child out after a brief time if indicated. Such ceremonies are often too long for most preschoolers. |
| 6. Reinforce child’s need to continue positive activities. |
| 7. Reassure child about their ability and determination to provide continued love and care. |
| 8. Provide transitional objects that seem important to child: deceased’s possessions, clothing, letters, or gifts they may have left for child. |
| 9. Prepare for surge of separation anxiety, sleeping problems, desire to sleep with the surviving parent, clinging behavior, and other temporary regressive behaviors. |
| 10. During first few weeks/months after the death, child may talk frequently about positive memories of parent and cling repeatedly where he/she has gone. |
| 11. Use available groups or bereavement programs for child. Engage others to listen and respond to questions if the parent is overwhelmed with own grief. |

| 6- to 8-year-olds |
|-------------------|
| 1. Inform even young children about parent’s worsening condition when death is imminent. |
| 2. Consider final visit with patient—children value final expressions of love. Prepare by describing patient’s condition and suggesting what children can say or do. Just touching the patient can be reassuring and helpful and exchanging gifts meaningful. |
| 3. Provide empathic support for initial responses to parent’s death. Permit return to normative activities. |
| 4. Have children attend traditional rituals and participate whenever possible. |
| 5. Children this age may ask blunt questions around time of the death: ‘Are you a widow now?’ |
| 6. Children’s expressions of grief are often brief and episodic. |
| 7. At this age, increased separation anxiety and sleeping difficulties are likely, often expressed also in stubbornness and problems with behavior. |
| 8. Reassure children of parent’s strength and commitment to continued care and love of the children despite grief of surviving parent. Remember to praise child for their efforts during such a difficult time. |
| 9. Give children objects or possessions of parent who died to provide a sense of connection and solace. |
| 10. Suggest participation in available bereavement programs. |
| 11. Encourage discussion with other adults or professionals when parent is too distressed to listen to child’s often joyous remembrance. |
| 12. Inform the school of the death and explore supportive services available to child should they become upset there. |

| 9- to 11-year-olds |
|-------------------|
| 1. Normalize both emotional avoidance at this age and emotional outbursts sometimes followed by embarrassment. |
| 2. Normalize increases in separation anxiety, behavioral and physical symptoms. |
| 3. Invite children to participate in ceremonies, either directly or indirectly through writing about parent or describing their views to other presenters at the rituals. Parents should be open to having their friends attend, as well. |
| 4. Follow child’s lead about returning to school after the death; keep in mind, however, that staying out of school beyond the final ceremonies is usually not helpful. |
| 5. Help child choose appropriate mementos belonging to the patient. |
| 6. Reestablish family routines. |
| 7. Teach and encourage mourning and participation in bereavement programs if available. |
| 8. Inform school of death and explore supportive services available to their child there. |

terminal stage in predictable deaths, later responses) that may clarify different outcomes; and

(3) Combining qualitative and quantitative analytic approaches provides a way to understand the realistic complexity of the area and populations under study. This may help to clarify when groups may be unknowingly combined whose findings cancel out clinically important variables.

This century has great promise to provide a rich harvest of useful approaches to the psychological support of children exposed to man-made and natural disasters, as well as diseases.

REFERENCES

1. Christ GH. Healing Children’s Grief: Surviving a Parent’s Death from Cancer. New York, NY: Oxford University Press; 2000.
2. Sandler IN, Ayers TS, Wolchik SA, et al. The family bereavement program: efficacy evaluation of a theory-based prevention program for parentally bereaved children and adolescents. J Consult Clin Psychol 2003;71:587–600.
3. Siegel K, Karus D, Ravesis VH. Adjustment of children facing the death of a parent due to cancer. J Am Acad Child Adolesc Psychiatry 1996;35:442–450.
4. Lin KK, Sandler IN, Ayers TS, Luecken L. Resilience in parentally bereaved children and adolescents seeking preventive services. J Clin Child Adolesc Psychol 2004;33:673–683.
5. Christ GH, Siegel K, Christ AE. Adolescent grief: “It never really hit me until it actually happened.” JAMA 2002;288:1269–1279.
6. Freud S. Mourning and melancholia. In: Strachey J, ed. Standard Edition of the Complete Psychological Works of Sigmund Freud.
13. Worden JW. Children and Grief: When a Parent Dies. New York, NY: Guilford Press; 1996.

20. Kwok OM, Haine R, Sandler I, et al. Positive parenting as a mediator of the relations between parental psychological distress and mental health problems of parentally bereaved children. J Am Acad Child Adolesc Psychiatry 1991;30:155–221.

22. Siegel K, Raves V, Karus D. Patterns of communication with children when a parent has cancer. In: Cooper C, Bader L, De-Nour AK, eds. Cancer and the Family. New York, NY: John Wiley & Sons; 1996:109–128.

23. Siegel K, Mesagno R, Christ G. A preventive program for bereaved children. Am J Orthopsychiatry 1999;60:168–175.

24. Rando T, ed. Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, Their Loved Ones and Their Caregivers. Ottawa, Canada: Research Press; 2000:155–221.

26. Christ G, Siegel K, Karus D, Christ A. Evaluation of a bereavement intervention. Social Work in End-of-life and Palliative Care 2005;1:57–81.

27. Lamont E, Christakis N. Complexities in prognostication in advanced cancer: “to help them live their lives the way they want to.” JAMA 2003;290:98–104.

28. Rando T. On the experience of traumatic stress in anticipatory and post death mourning. In: Rando T, ed. Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, Their Loved Ones and Their Caregivers, Ottawa, Canada: Research Press; 2000:155–221.

31. Kranzler E, Shaffer D, Wasserman G, Davies M. Early childhood bereavement. J Am Acad Child Adolesc Psychiatry 1990;29:513–520.

32. van Eerdewegh M, Bien M, Parilla R, Clayton P. The bereaved child. Br J Psychiatry 1982;140:23–29.

33. Cheifetz PN, Stavrakakis G, Lester EP. Studying the adaptation of bereaved adolescents. J Palliat Care 1987;3:30–34.

34. Rauch P, Muriel A, Cassen N. Parents with cancer: who’s looking after the children? J Clin Oncol 2002;21:4399–4402.

35. Gray R. The role of the surviving parent in the adaptation of bereaved adolescents. J Palliat Care 1987;3:30–34.

36. Christ G, Siegel K, Mesagno R, Christ A. A preventive program for bereaved children. Am J Orthopsychiatry 1999;60:168–175.

37. Worden J. Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner. 2nd ed. New York, NY: Springer; 1991.

38. Christ G, Siegel K, Mesagno F, Langosch D. A preventive intervention program for bereaved children: problems of implementation. Am J Orthopsychiatry 1991;61:168–178.

39. Ginsburg H, Oppen S. Piaget’s Theory of Intellectual Development. 3rd ed. Englewood Cliffs, NJ: Prentice Hall; 1987.

40. Hoven CV, Mandell DJ, Duarte CS. Mental health of New York City Public School children after 9/11: an epidemiologic investigation. In: Coates SW, Rosenthal JL, et al, eds. September 11: Trauma and Human Bonds Relational Perspectives Book Series. Hillsdale, NJ: Analytic Press, Inc.; 2003:51–74.

41. Hooyman N, Kramer B. Living through Loss. New York, NY: Columbia University Press; 2006.

42. Rauch P, Muriel A, Cassen N. Parents with cancer: who’s looking after the children? J Clin Oncol 2002;21:4399–4402.

43. Christ G. Providing a home-based therapeutic program for widows and children. In: Greene P, Kane D, Christ G, Lynch S, Corrigan M, eds. FDNY Crisis Counseling: Innovative Responses to 9/11 Firefighters, Families, and Communities. New York, NY: Wiley; 2006.

44. Green P, Kane D, Christ G, Lynch S, Corrigan M, eds. FDNY Crisis Counseling: Innovative Responses to 9/11 Firefighters, Families, and Communities. New York, NY: Wiley; 2006.

45. Centers for Disease Control. Rates of homicide, suicide, and firearm-related death among children—26 industrialized countries. MMWR 1997;46:101–105.

46. Wolfe J, Klar N, Grier H, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. JAMA 2000;284:2469–2475.