

# Educational Needs Among Pediatricians Regarding Caring for Terminally Ill Children

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**Background:** According to the Accreditation Council on Graduate Medical Education and the Ambulatory Pediatrics Association, pediatricians need to be instructed in caring for terminally ill children as a part of residency training. However, a systematic approach to education in end-of-life care is lacking in most residency programs.

**Objectives:** To assess pediatricians' self-perception of their coping skills regarding death and dying at The New York Hospital–Cornell Medical Center, New York City, NY, if they felt further support and education were needed in this area, and which modes of instruction respondents thought would be most useful.

**Methods:** Data based on a questionnaire distributed to pediatricians at The New York Hospital are presented.

**Results:** The following topics are discussed: (1) existing level of education and support in caring for terminally ill patients; (2) attitudes of pediatricians regarding discussions of diagnosis and prognosis with dying children and their families; (3) pediatricians' perceived need to limit emotional involvement with terminally ill children; (4) attendance of funeral or memorial services of patients by pediatricians; (5) experience of patient death as a failure; and (6) expressed need for support and instruction in death and dying based on level of training.

**Conclusion:** Educational interventions and support in this area are needed.

*Arch Pediatr Adolesc Med.* 1998;152:909-914

**Editor's Note:** This study augments that of Bowen and Marshall in this issue. There can be no doubt that we're not meeting a major need of our patients' families.

Catherine D. DeAngelis, MD

**T**HE DEATH of a patient is known to be a stressful experience for physicians.<sup>1,2</sup> The death of a child is even more disturbing because it contradicts the natural order of things: children are not supposed to die.<sup>1,3</sup> Nevertheless, pediatric residents care for a significant number of terminally ill children during their training.<sup>4-6</sup> In 1983, Sack et al<sup>6</sup> interviewed third-year pediatric residents at 4 western US university training programs about their experiences in caring for dying children. The authors reported that pediatric house officers cared for an average of 35 dying children during their first 2½ years of residency training. With the development of increasing technology in neonatal and pediatric critical care, as well as the growing numbers of children with acquired immunodeficiency

syndrome, one can speculate that this number is even greater today. In addition, the secularization and institutionalization of death has meant that fewer societal support systems exist to facilitate bereavement. Increasingly, patients and families turn to health care professionals for support and comfort during this time.<sup>3,7,8</sup>

Recent surveys have reported that a majority of parents who have experienced the death of a child express dissatisfaction with the manner in which physicians and other hospital staff handle the situation.<sup>9</sup> The parents indicated that they wanted their child's physician to communicate more openly with them, to share in their grief, and to provide them with support and comfort.<sup>9</sup>

*See also pages 837 and 852*

For pediatricians to effectively counsel and support bereaved parents, adequate educational resources and psychological support must be provided during residency training. Behnke et al,<sup>7</sup> in a survey of pediatric residents at a Florida uni-

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## PARTICIPANTS AND METHODS

No validated assessment tools exist to assess physician attitudes toward terminal illness and educational needs surrounding pediatric death and dying. A questionnaire was devised by one of us (S.K.) consisting mainly of 4 components (**Figure 1**): (1) basic demographic information (age, sex, level of training, and if applicable, subspecialty); (2) information about the respondent's previous undergraduate and graduate medical course work in end-of-life care; (3) multiple-choice questions, as well as Likert-type items (with a 1-5 range of agree to disagree) assessing different aspects of caring for terminally ill children; and (4) items concerning the physician's perception of his or her own ability to care for dying patients, if further instruction would be useful, and specifically which teaching format(s) would be most helpful.

Between April 10 and June 15, 1996, 131 questionnaires were distributed to full-time pediatric medical staff at The New York Hospital–Cornell Medical Center. Questionnaires were completed anonymously. All completed questionnaires were collected with the assistance of department secretaries to ensure anonymity. Exemption from obtaining informed consent was given by the hospital institutional review board.

Of 131 questionnaires distributed, 74 completed questionnaires were returned (response rate of 56%). Forty-

seven percent of house staff, 50% of fellows, and 74% of attending physicians surveyed returned the questionnaire.

### DATA ANALYSIS

Raw percentages were calculated and responses were analyzed with respect to level of training. No statistical analyses were performed as the validity and reliability of the questionnaire have not yet been determined.

### PARTICIPANTS

The average age of the residents, fellows, and attending physicians responding was 28.9, 32.3, and 43.3 years, respectively. Male and female responses were distributed evenly among fellows and attending physicians; however, there was a 1:3.8 male-female ratio among responding residents, which reflects the preponderance of women on the pediatric house staff at that time.

The fellows and attending physicians surveyed represented all major subspecialty areas within pediatrics as well as primary care pediatrics. Approximately one third of the respondents ( $n = 23$ ) belonged to subspecialties that would naturally encounter a greater number of patient deaths, such as hematology-oncology, critical care medicine, neonatology, and infectious diseases. This group consisted only of fellows and attending physicians, and the latter had a preponderance of male responses.

versity hospital, reported that most residents did not feel confident in counseling bereaved families; they considered their lack of formal training to be a major factor contributing to their lack of confidence. Sack et al,<sup>6</sup> in their review of death education curricula for pediatric residents in 4 western US university programs, found little evidence of the use of a systematic, integrated approach to pediatric death and dying, despite the magnitude of clinical exposure.

According to the Accreditation Council on Graduate Medical Education's recent guidelines for residency education in pediatrics, formal instruction on the "impact of . . . terminal conditions and death on patients and their families" must be provided to pediatric residents.<sup>10</sup> Recently, the Ambulatory Pediatrics Association issued specific curricular guidelines on death and terminal illness: through the course of their training, pediatric residents are expected to "understand how to provide skillful medical care and empathetic support to the terminally ill child and his/her family [as well as] understand one's personal responses and feelings when dealing with death and dying."<sup>11</sup> The Ambulatory Pediatrics Association also stated that residents "need to share feelings with other [colleagues] during times of stress/death [of a patient]."<sup>11</sup> However, according to a report by the American Medical Association in 1993, only 26% of primary care residency programs nationwide offered training in the care of dying patients.<sup>12</sup> We conducted a comprehensive review of the literature and found that limited attention has been paid to pediatric approaches to death and dying, specifically with respect to the feelings and attitudes of pediatric interns and residents.

The percentage of US medical schools that offer instruction in terminal care has nearly doubled in the last 2 decades, from 50% in 1972 to 89% in 1991.<sup>13</sup> However, teaching on palliative care in medical school tends to be fragmented, consisting mostly of lectures scattered primarily in the first 2 years and often devoid of any clinical context.<sup>12-15</sup> Course work in this area is mostly elective and students are usually not encouraged to examine their personal reactions to death and dying.<sup>16</sup>

In this context of limited educational resources and support structures with respect to terminal illness, both in undergraduate and graduate medical education, we proposed to assess pediatricians' perceptions of their coping skills surrounding death and dying at The New York Hospital–Cornell Medical Center, a tertiary care center and major university hospital offering training in general pediatrics as well as several pediatric subspecialties. The following topics were examined: (1) existing level of education and support in caring for terminally ill patients; (2) attitudes of pediatricians regarding discussions of diagnosis and prognosis with dying children and their families; (3) pediatricians' perception of need to limit emotional involvement with terminally ill children; (4) attendance of funeral or memorial services of patients by pediatricians; (5) experience of patient death as a personal failure; and (6) perceived need for support and instruction in death and dying.

## RESULTS

Sixty-four percent of residents and approximately 50% of fellows and attending physicians surveyed reported hav-

1. (A) Please specify your level of training.  PL1  PL2  PL3  
 Fellow  Attending

(B) If you are a fellow or attending, please specify your subspecialty \_\_\_\_\_

(C) Please list the number of years you have been in the above specialty \_\_\_\_\_ years

(D) Your age \_\_\_\_\_ (E) Your sex  Male  Female

2. (A) Did you receive any formal education (ie, didactic lectures and/or direct patient care) with respect to caring for terminally ill patients and/or dealing with issues of death and dying in medical school?  Yes  No

(B) Have you received any such training during your residency?  Yes  No

(C) If you are a fellow or attending, did you receive any such education during fellowship?  Yes  No

3. For the following statements, please indicate the extent to which you agree or disagree on a 5-point scale ranging from strongly agree to strongly disagree with a neutral choice in the middle (1 = strongly agree, 2 = agree, 3 = no opinion, 4 = disagree, and 5 = strongly disagree)

A. I feel as comfortable taking care of a dying child as with any other patient. 1 2 3 4 5

B. Dealing with the family of a dying child is difficult. 1 2 3 4 5

C. One of the reasons why doctors choose their profession is to deal with their fear of dying/death. 1 2 3 4 5

D. In my personal experience, the death of a child is more difficult to deal with than the death of an adult. 1 2 3 4 5

E. Parents of terminally ill children should be given a realistic and accurate prognosis. 1 2 3 4 5

Please answer the following set of 2 questions with respect to the specific age groups:

F. The terminally ill child should also be told his/her diagnosis and prognosis if the parents give their consent.

Ages 4 and under 1 2 3 4 5

Ages 5 to 10 years 1 2 3 4 5

Ages 10 to 14 years 1 2 3 4 5

Ages 14 to 18 years 1 2 3 4 5

G. The HIV-infected child should also be told his/her diagnosis and prognosis if the parents or legal guardians give their consent.

Ages 4 and under 1 2 3 4 5

Ages 5 to 10 years 1 2 3 4 5

Ages 10 to 14 years 1 2 3 4 5

Ages 14 to 18 years 1 2 3 4 5

H. When medicine can offer nothing more to the patient, I like to give the patient and family more space and not become more involved than necessary. 1 2 3 4 5

I. In dealing with a terminally ill child one must limit becoming emotionally involved. 1 2 3 4 5

J. There is a tendency to favor life-prolonging measures for children suffering from terminal illnesses. 1 2 3 4 5

K. House staff need support in dealing with dying patients. 1 2 3 4 5

4. Please select 1 option for the following statement:  
I have experienced the death of a child as a personal failure.  
 Always  Sometimes  Rarely  Never

5. I have personally been involved in discussions regarding initial diagnosis and ultimate prognosis with the family of a terminally ill child.  Yes  No

6. (a) Have you experienced the loss of a friend or relative?  Yes  No

(b) If you answered "yes" to the above question, do you believe that this experience has helped you feel more comfortable in dealing with issues of death/dying in your career thus far?  Yes  No

7. Taking care of terminally ill children is difficult because of: (Please rate each from scale of 1 to 5, with 1 being the least significant and 5 being the most significant.)

Lack of previous relationship with the child/family  
 Lack of open communication regarding issues of death/dying with family/patient  
 Medical regimens that often compromise the child's quality of life  
 Lack of personal sense of competence in dealing with issues of death/dying as a physician

8. After the death of one of my patients, I feel: (you may choose more than 1 answer)

anger  sadness  isolated  hopeless  powerless  
 fearful  numb  relieved  exhausted

9. I feel I can turn to resources within the department to assist me in the process of dealing with my own grief.  Yes  No

10. After the death of one of my patients, I have turned to \_\_\_\_\_ for support. (You may choose more than 1 answer.)

Family member  Nurse  
 Friend  Social work  
 House staff member  Chief Resident  
 Program director  Mental health professional  
 Chaplain/Rabbi/Priest/Other religious leader  Other (please specify)

11. I have wanted to attend funeral/memorial services after the death of one of my patients.  Yes  No

12. I have attended funeral/memorial services after the death of one of my patients.  Yes  No

If you answered "no" to the above question, please complete the following statement: I have not been able to attend a funeral/memorial service because: (you may choose more than 1 answer)

No time  
 Did not receive any information  
 Not interested  
 Did not feel the need to attend  
 Have not seen other physicians attend such services  
 Could not be relieved of my patient care responsibilities  
 It is not a part of my role as a physician  
 Would not feel comfortable in such a situation

13. I feel adequately prepared from my training thus far to deal comfortably with death and dying among my patients.  Yes  No

14. Further instruction in dealing with death and dying would be useful.  Yes  No

15. If you answered "yes" to the above question, please rate from 1 to 5 the following suggestions (with 1 being the least useful to 5 being the most useful):

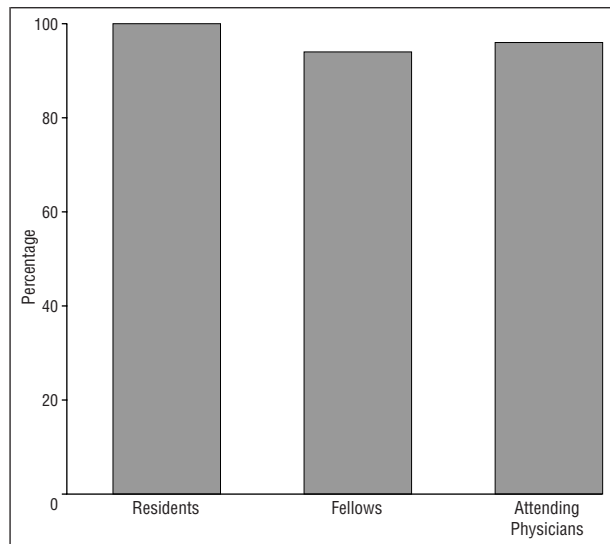
Being encouraged to attend funeral/memorial services  
 Meeting with a mental health professional (with expertise in the area of death/dying) in a group setting shortly after the death of a patient  
 Formal didactic lectures (ie, as a part of noon conferences)  
 Meeting one-on-one with a bereavement counselor

Thank you once again for your participation. If you have any comments, feel free to use the space below.

Figure 1. Questionnaire distributed to full-time medical staff in the Department of Pediatrics, New York Hospital–Cornell Medical Center, New York City.

ing received some form of instruction on issues related to end-of-life care during medical school. Eight percent of residents, 28% of fellows, and 34% of attending phy-

sicians surveyed had been exposed to this education during their residency. Similarly, 11% of fellows and 29% of attending physicians stated that they had received train-



**Figure 2.** Percentage of physicians discussing prognosis with the parents of a terminally ill child.

ing during their fellowships. Twenty-five percent of the fellows and 64% of the attending physicians belonging to subspecialties likely to encounter greater numbers of patient deaths stated that they had received some instruction in end-of-life care during fellowship.

All groups agreed that parents of terminally ill children should be given a realistic and accurate prognosis (**Figure 2**). Respondents were more likely to discuss issues of diagnosis and prognosis with terminally ill children and children infected with the human immunodeficiency virus with increasing age of the child (**Table 1** and **Table 2**).

There was no clear agreement among the pediatricians surveyed with respect to a perceived need to limit emotional involvement in dealing with dying children and their families. Sixty-three percent of residents, 81% of fellows, and 64% of attending physicians who responded expressed a desire to attend funeral services after the death of their patients. None of the residents and 25% of the fellows had actually done so. The major reasons cited for not being able to attend funerals were lack of time and not having a formal mechanism to be relieved of patient care responsibilities.

When asked if they had ever perceived the death of a patient as a personal failure, 60% of residents and 56% of fellows surveyed stated that this was rarely or never the case. Sixty-one percent of all attending physicians and 73% of attending physicians working in specialties with a higher mortality rate said that they sometimes viewed the death of a patient as a personal failure.

One hundred percent of resident physicians, 83% of fellows, and 90% of attending physicians expressed a need for further support in dealing with death and dying. Eight percent of residents, 28% of fellows, and 26% of attending physicians felt that there were adequate existing support structures within the department of pediatrics at The New York Hospital. All 3 groups cited family members and friends as the major sources of support to whom they would turn for assistance in such situations. Fellows and attending physicians working in ar-

**Table 1.** Percentage of Physicians Willing to Discuss Diagnosis and Prognosis With a Terminally Ill Child

Type of Physician	Age of Child, y			
	≤4	5-10	11-14	15-18
Residents	24	64	92	92
Fellows	31	50	75	75
Attending	39	55	81	90

**Table 2.** Percentage of Physicians Willing to Discuss Diagnosis and Prognosis With a Child Infected With Human Immunodeficiency Virus

Type of Physician	Age of Child, y			
	≤4	5-10	11-14	15-18
Residents	24	68	85	92
Fellows	38	62	75	75
Attending	36	61	83	93

eas with higher numbers of patient deaths had responses similar to those from the group as a whole.

Thirteen percent of residents, 56% of fellows, and 71% of attending physicians stated that they felt adequately prepared to deal with end-of-life issues. Ninety-five percent of the residents and fellows and 64% of attending physicians reported that further instruction about issues of death and dying would be useful. Meeting with a mental health professional with expertise in the area of end-of-life issues in a group setting shortly after the death of a patient and didactic lectures were the 2 modes of instruction perceived to be most useful. Once again, fellows and attending physicians in the subspecialties dealing with a large number of terminally ill patients had responses similar to those from the group as a whole.

#### COMMENT

We found that at least 50% of pediatricians surveyed had received some teaching in medical school and a much smaller number had received any such instruction during postgraduate training. Sack et al<sup>6</sup> and Behnke et al<sup>7</sup> independently reported on the lack of formal training in bereavement counseling for pediatricians-in-training as well as the need for an integrated curriculum about pediatric death and dying. These results reflect larger nationwide trends; education in end-of-life care is occurring in nearly 90% of US medical schools but only in 26% of postgraduate primary care residency training.<sup>12</sup> This is ironic because it is during internship and residency that physicians first assume primary responsibility for patient care and personally address issues of death and dying.

In our study we found that all groups surveyed unanimously agreed that parents of terminally ill children have a right to be informed about the diagnosis and prognosis of their child's illness (Figure 2). Wiener<sup>17</sup> conducted a questionnaire survey of pediatric residents and attending physicians in a Midwestern clinic, a New York

City hospital, and office practices in the Long Island, NY, suburbs with respect to their attitudes toward caring for terminally ill children. He similarly reported that a majority of the respondents (71%) agreed that parents should be informed of these matters in an open manner. Wiener found that most of the respondents believed that children should seldom or never be informed of the nature of their illness. However, the majority of pediatricians surveyed by Wiener favored disclosure if the child directly requested this information. The respondents to our survey would be more likely to engage in discussions of diagnosis and prognosis with terminally ill children as well as with children with human immunodeficiency virus infection with increasing age of the child (Table 1 and Table 2). This displays an appropriate sensitivity to the developmental status of the child and his or her ability to understand the concept of death. In our study, the overall trend toward a more open attitude of discussion with terminally ill children is in agreement with recent shifts among children and their families to take a more active role in their health care management.

At least 60% of respondents expressed a desire to attend funeral or memorial services but none of the residents and only one fourth of fellows had actually attended such services. The major reason cited for not being able to attend funerals was other clinical responsibilities. We did not find studies in the literature that addressed the issue of funeral attendance of patients among pediatricians, but Sack et al<sup>6</sup> found that less than 50% of residents had any contact with the family after a child's death. Attending the funeral of a patient offers a means of closure. It can be a time in which the physician can express his or her grief and sense of loss in an organized way with the family, and among other colleagues if they are also present. The absence of an existing mechanism within the residency programs to facilitate funeral attendance reflects a larger lack of a systematic approach to pediatric death and dying.

The pediatricians surveyed expressed ambivalence with respect to the degree of emotional involvement they would choose to maintain with dying patients and their families. Schowalter<sup>18</sup> wrote about his experiences as a child psychiatry consultant working with pediatric house officers caring for terminally ill children and their families at Yale–New Haven Hospital, New Haven, Conn. He described how “pediatric house officers treating dying children often tend to withdraw from the patient and from their own feelings.” Wiener<sup>17</sup> also alludes to “a conflict [among health care professionals] in the care of terminally ill children between forces of compassion pressing toward involvement and forces pressing toward avoidance and protection from painful feelings.” Behnke et al<sup>19</sup> assessed behavioral and psychophysiologic responses among pediatric house officers who had experienced the death of a patient. They observed that physicians “do experience a grief reaction [that is] similar to grief responses experienced with the death of a loved one.” It is plausible that in the context of limited support structures to facilitate the acknowledgment and processing of personal grief, many pediatricians-in-training may choose to maintain a distance so as to be able to continue to function and discharge their duties as expected.

Attending pediatricians were more likely to perceive the death of a child as a personal failure than other house officers. Sack et al<sup>6</sup> discussed the way in which physicians have extremely high expectations of their ability to preserve life. In this context, death is often experienced as failure. Attending pediatricians who supervise the overall management of patients' cases are likely to feel a greater degree of direct responsibility to the patient and, accordingly, more commonly view patient death as a personal failure.

All groups surveyed expressed a desire for further emotional support to assist them as they cared for terminally ill children. A minority of respondents stated that there were adequate existing support structures in the department. With increasing level of training, there was a trend among the respondents to feel more prepared in dealing with terminally ill children and their families; however, almost all residents and fellows surveyed and a majority of attending physician stated that further instruction in issues of death and dying would be useful.

This study is limited by several factors. The reliability and the validity of the questionnaire has not been established. This survey also represents the views of a relatively small number of pediatricians at one university hospital in the northeastern United States. Finally, this survey may be subject to a self-selection bias, in that the pediatricians responding may not be representative of the pediatric department as a whole.

To maintain anonymity, no attempt was made to contact those physicians who did not return the questionnaire. We can speculate that the residents and fellows not responding may have been so overwhelmed by the daily demands of medical training that they did not have time to complete the questionnaire. Perhaps the subject matter of death and dying was itself frightening or threatening and this also made it difficult for some physicians to complete and return the questionnaire. In any case, we feel that the 56% overall response rate underestimates the need for further support and education in this area.

Our survey yielded important results that help to delineate how pediatricians at one university hospital are coping with issues of death and dying. We found a consensus between the responses of the subgroup of fellows and attending physicians working in areas with higher degree of exposure to patient death and those of the group surveyed as a whole. Additionally, our findings concur with those of previous authors<sup>4-7,9,18</sup>; thus far there has been little systematic effort expended to assist pediatricians-in-training to develop clinical and psychosocial skills needed for effective management of terminally ill children and their families.

## RECOMMENDATIONS

Based on the results of the questionnaire, a review of the literature, and informal discussions with faculty members at several institutions, the following suggestions are offered:

(1) A systematic, integrated, didactic curriculum on caring for dying children and their families needs to be established as part of pediatric residency education. This should be taught throughout all 3 years of residency training.

The dying patient and his or her family have been noted to be good teachers.<sup>16</sup> Forums should be estab-

lished in which terminally ill children, their families, and/or bereaved parents and siblings can share their experiences with house staff.

The usefulness of role-playing exercises in fostering enhanced communication skills among residents, as well as improved physician-patient interaction, has been described.<sup>16</sup> A comprehensive curriculum on end-of-life care ought to include role-playing scenarios specific to terminal illness. In this manner, residents can “practice” difficult situations in a peer group setting, such as informing parents that their child has a terminal illness, discussing do-not-resuscitate orders with a child’s family, and counseling a bereaved parent after a death in the emergency department or intensive care unit setting.

Caring for terminally ill children is a multidisciplinary task, commonly involving not only pediatricians but also child psychiatrists, nurses, psychologists, social workers, nutritionists, art therapists, chaplains, and volunteers. The process of educating residents about end-of-life care will necessarily involve faculty from all of these disciplines.

(2) After each pediatric death, physicians, nurses, and other support staff who were closely involved with the care of the patient should meet with a pediatric liaison psychiatrist or another professional with expertise in bereavement counseling to discuss emotional reactions and coping difficulties. In such a setting, pediatricians-in-training can explore their anxieties and fears surrounding death and dying and experience a sense of validation in a peer group setting.

(3) Attending pediatricians must be trained in caring for terminally ill children and their families so that they can serve as role models for residents.

(4) Hospice or palliative care rotations should become an integral part of standard pediatric residency training to assist pediatricians in becoming acquainted with the biopsychosocial issues surrounding terminal illness.

(5) Attendance of funerals of patients should be encouraged and facilitated as part of residency experience.

## CONCLUSIONS

Caring for terminally ill children is one of the most challenging and stressful experiences for pediatricians. Educational and emotional support systems need to be implemented into the structure of pediatric residency training programs to enable pediatric house staff to successfully

manage their own feelings and responses to death and dying, so that they can in turn more effectively serve the needs of their patients and their patients’ families.

Accepted for publication April 10, 1998.

We acknowledge the support and guidance of Paul Edelson, MD, Judith Kaufman, PhD, and Patricia Muehsam, MD, as well as thank the Pediatric Special Studies team at The New York Hospital–Cornell Medical Center, New York City. We also thank Munish Khaneja, MD, for his technical support.

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