Cause of Death of Infants and Children in the Intensive Care Unit: Parents' Recall vs Chart Review

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Abstract

Background—More than 55 000 children die annually in the United States, most in neonatal and pediatric intensive care units. Because of the stress and emotional turmoil of the deaths, the children's parents have difficulty comprehending information.

Objectives—To compare parents' reports and hospital chart data on cause of death and examine agreement on cause of death according to parents' sex, race, participation in end-of-life decisions, and discussion with physicians; deceased child's age; unit of care (neonatal or pediatric); and hospital and intensive care unit lengths of stay.

Methods—A descriptive, correlational design was used with a structured interview of parents 1 month after the death and review of hospital chart data. Parents whose children died in intensive care were recruited from 4 South Florida hospitals and from Florida Department of Health death records.

Results—Among 230 parents, 54% of mothers and 40% of fathers agreed with the chart cause of death. Agreement did not differ significantly for mothers or fathers by race/ ethnicity, participation in end-of-life decisions, discussions with physicians, or mean length of hospital stay. Agreement was better for mothers when the stay in the intensive care unit was the shortest. Fathers' agreement with chart data was best when the deceased was an infant and death was in the pediatric intensive care unit.

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Conclusions—Death of a child is a time of high stress when parents' concentration, hearing, and information processing are diminished. Many parents have misconceptions about the cause of the death 1 month after the death.

The death of a child is devastating for the child's parents. In the United States, 55 000 infants and children die annually,[1] most in neonatal or pediatric intensive care units (NICUs and PICUs).[2,3] These ICUs, with their high noise levels, equipment, and fast pace, can impose additional stressors on parents in a time of crisis.[4] Because of the stress and emotional turmoil that parents experience around the time of death of their infant or child, the decisions they may need to make, and the added stress of the ICUs, parents often have difficulty comprehending or grasping the information shared with them.[5,6] Differences in language, cultures, and educational levels can add to difficulties in comprehension and in making end-of-life decisions.[7]

Studies[4,8–10] on parents' understanding of information shared around the time of their child's death most often have been retrospective, requiring parents to recall information 1 to 10 years after the death, and study samples have consisted mainly of white, English-speaking participants. The primary aim of this study was to compare the cause of an infant's or a child's death as reported by parents in 3 racial/ethnic groups (white, black, Hispanic) with cause of death reported in hospitals' chart data. A secondary aim was to examine differences between each child's mother and father according to the parents' race/ethnicity (white, black, Hispanic), participation in end-of-life decisions, and discussion with physicians; deceased child's age group; unit of care (NICU, PICU); and length of hospital and ICU stay.

Causes of Death

Leading causes of death in infants differ from those in children. Most deaths in infants in the United States (56.1%) are attributed to 5 leading causes[11]: congenital anomalies and genetic disorders (20.1%), disorders related to prematurity and low birth weight (16.9%), sudden infant death syndrome (8.2%), maternal complications of pregnancy (6.3%), and accidental or unintentional injury (4.6%). Leading causes of death in children 1 to 19 years old[11] are accidents or unintentional injuries (38.8%), assaults (12.4%), malignant neoplasms (8.6%), suicide (8%), illnesses and diseases (7.7%), and congenital anomalies or genetic disorders (4.7%). No matter the cause, the death of an infant or child is a devastating, stressful, high anxiety situation for the parents, especially deaths that occur in ICUs.[4,8,9]

Parents' Distress and Information Recall

For the parents, high levels of stress and distress around the time of death of an infant or a child are associated with problems in comprehending or grasping information provided. Lannen et al[12] studied parents' ability to absorb information that the parents' child had incurable cancer and tried to identify factors associated with the parents' ability to absorb the information. Of the 449 parents in the study, 60% reported being able to absorb the information that their child's cancer was incurable, 29% reported they were not, and 12% stated they did not receive any information. In an earlier study[13] of 46 parents within 3 years of diagnosis of cystic fibrosis in their children, 76% lacked understanding of the disease,

although more than 33% admitted having understood or remembered something about what the physician had told them. Meert et al[4] found that because of the emotional turmoil associated with a child's death, parents had difficulty comprehending information provided at that time.

Methods

Research Design

The data reported here are from a longitudinal study on parents' health and functioning after the ICU death of an infant or child. The study was approved by the appropriate institutional review boards and was carried out according to the ethical standards set forth in the Helsinki Declaration of 1975. Parents (white non-Hispanic, black non- Hispanic, Hispanic or Latino) who had lost a child in the NICU or PICU were identified by clinician coinvestigators at each of 4 hospitals in South Florida or identified through death records from the Florida Department of Health, Office of Vital Statistics.

A letter was sent by the study project director to each family (in Spanish and English) describing the study and containing the study telephone number should parents choose not to participate. For parents who had not responded, the letter was followed by a telephone call 2 weeks later by research assistants who screened parents for inclusion and exclusion criteria, described the study, answered parents' questions, obtained verbal consent for parents who chose to participate, and scheduled a first interview, where written consent was obtained. Parents were included if they were able to understand spoken English or Spanish, had a neonate from a singleton pregnancy who lived for more than 2 hours in the NICU, or had a deceased child 18 years or younger who lived at least 2 hours in the PICU. Exclusion criteria were a multiple pregnancy with a deceased newborn, child living in a foster home before hospitalization or whose injury was suspected child abuse, and parent's death in the illness or injury event (eg, motor vehicle crash).

Measures and Data Collection

All data were collected by bilingual (English and Spanish) research assistants who were health professional students with advanced clinical degrees and were trained in study methods. Interviews with parents in English or Spanish were conducted in the parents' home at a time convenient for the parents 1 month after death of the infant or child. By 1 month after the death, the initial shock and numbness have subsided, funeral rituals have been completed, and friends and family have returned to their own lives but circumstances surrounding the death can be recalled accurately. Parents were asked specific questions about the death, decisions and participation in these decisions around the time of the death, treatments, and the cause of the death. Questions included the following: Did you discuss the child's progress with the physician? Was your child resuscitated, and who made this decision? Was any treatment stopped before your child's death and who made this decision? What was the cause of the death. Answers to these structured questions and demographic data including each parent's age, sex, race/ethnicity, education, income, marital status (single, partnered), and employment status were recorded at the time of the interview on standard data collection forms by the research assistants who conducted the interviews.

Hospital chart data included the deceased's age, race/ethnicity, sex, length of stay in the ICU and in the hospital, treatments, diagnosis at the time of admission, cause of death, and family involvement.

Data Analysis

Data on cause of the infant's or child's death collected from the hospital chart and information provided by the mother and/or father during the interview were recorded and tallied in a table that included cause of death by hospital chart, by mother's report, and by father's report.

Agreement (concordance) on cause of death between hospital chart data and parent's report was determined by consensus (yes, no, similar) by a panel of 2 physicians and 2 nurses with doctorates. Initially each panel member independently scored agreement (yes, no, similar) on causes of death from hospital chart data with that of the parent's reports. Any scoring inconsistencies were reviewed and discussed by the total panel until consensus was reached.

Categorical data were summarized as frequencies and percentages; continuous data, as means and standard deviations. Agreement (concordance) within parent couples was compared. All other analyses were done for mothers and fathers separately. Agreement within parent couples was compared on each parent's race/ ethnicity, discussions with physicians on the prognosis of the deceased infant or child, the parent's participation in end-of-life decisions, the deceased child's age group, and unit of care (NICU, PICU) by using χ^2 analyses. Mean lengths of hospital and ICU stay were compared across agreement (concordance) groups by using 1-way analysis of variance. The P level for statistical significance was set at .05.

Results

Sample

Of 318 eligible families contacted, 146 refused to participate in the study (46%), and 172 agreed to participate (54%). The final study sample (Table 1) consisted of 230 parents (162 mothers, 68 fathers) whose infant or child died in the NICU (n = 72) or the PICU (n = 100). Fathers were a mean of 5.6 years older than the mothers. A total of 78% of the parents were minorities (Hispanic and black). Most parents were married or living with a partner; more than half of the parents had had some education beyond high school. The majority of families had an annual income less than $50 000.

Deceased Children

About half (55%) of the deceased infants and children were boys (Table 2). The mean age of the deceased infant or child was 39.4 (SD, 64.3) months. Mean lengths of hospital and ICU stay were slightly longer for infants in the NICU than for children in the PICU.

Major causes of death varied by chart review and by mothers' and fathers' reports. From chart review, the top 4 causes of death were respiratory problems, prematurity, congenital anomalies, and infections (Table 3). The top 4 causes of death reported by mothers were

prematurity, respiratory problems, accidental injury, and infection; the top 4 reported by fathers were respiratory problems, infections, surgical complications, and accidental injury.

Agreement of Chart Data and Parents' Reports

A total of 54% of mothers but only 40% of fathers reported a cause of death that was consistent with data in the hospital chart (Table 4). In 39 of the 56 couples (mother and father of the same child), both parents were in the same agreement category: 16 couples (28%) in the agree with chart category, 15 couples (27%) in the disagree with chart category, and 8 couples (14%) in the close to chart category χ^2=33.9; df=4; $P<.001$). In the remaining 17 couples, mothers' agreement category differed from the fathers' agreement category. Agreement on chart cause of death did not differ significantly for mothers or fathers by race/ethnicity, by discussing the child's prognosis with the physician, or by participating in end-of-life decisions. Mothers' agreement with chart review did not differ significantly by unit of care; however, significantly more fathers of NICU infants were not in agreement compared with fathers of PICU children. Mean length of hospital stay did not differ by agreement for mothers or fathers. Mean length of ICU stay differed significantly by agreement for mothers, but not for fathers. Mean days of ICU stay were shortest for the group of mothers in agreement with chart data and longest for the group of mothers whose stated cause of death did not agree with the chart data. The age group of the infant or child was not significantly related to agreement for mothers, but it was for fathers. Most fathers of infants (53%) were in agreement with chart data. Most fathers of school-age children (57%) and adolescents (64%) named a cause of death that was close to what was listed in the chart.

According to chart data, most of the 172 deceased infants and children died after resuscitation was unsuccessful, limiting treatments or supportive therapies and withdrawal of life support. Health care providers recorded that 105 families (61%) participated in end-of-life decisions, 13 families (8%) did not participate, and participation of 13 families (8%) was not charted. For 40 families (23%), no end-of-life decision was made. Therapies discontinued included mechanical ventilation, administration of intravenous fluids, use of a feeding tube, and blood pressure monitoring. Therapies limited included feeding and certain drugs. Do-not-resuscitate orders were present for 47 of the 52 children (90%) who died after treatment was limited. Once life support was removed, 80% of the infants and children died within 1 hour. Most mothers (62%) and fathers (75%) reported that they were with their infant or child at the time of death.

Discussion

In this study, we controlled for parents' recall by collecting data 1 month after the death of the parents' infant or child. The study sample consisted of a racially/ethnically diverse group of parents who lost an infant or child. The variation in reported causes of death by mothers' and fathers' reports and according to chart review might be due to problems in parents' understanding of the child's changing condition and prognosis; problems between parents and providers in communication, language, and/or culture; or in recorded chart data. Other research[4,10,14–16] indicates that before the death of their infant or child, parents are frightened by seeing the infant or child in pain and suffering, being unable to communicate

with the child, and may be overwhelmed or intimidated by lack of information or by misinformation about the child's prognosis or impending death. During this time of high stress and anxiety, parents' concentration is diminished, affecting both receiving and processing of information. Studies[10,12,14,16,17] have documented parents' denial of information shared and lack of remembrance of specifics of information shared at this time.

Our findings provide further evidence of this problem. Only 54% of mothers and 40% of fathers agreed with chart data on cause of death. Length of ICU stay, but not length of hospital stay, differed by whether or not mothers' cause of death agreed with the chart. This was not true for fathers. For the mothers, mean ICU stays were shortest for those who agreed with chart data on cause of death and longest for the mothers who did not agree with the chart data. For more immediate deaths, little to no change may occur in the child's prognosis and cause of impending death. Their condition, prognosis, and potential cause of death for children whose death is not immediate may change over days. Updates and the flow of this information may be delayed or confusing for mothers who may already be compromised by stress that interferes further with their comprehension of information. In addition, delays or problems may occur in recording such changes in condition in the patient's chart.

Agreement with chart cause of death did not differ significantly for mothers or fathers by discussions of the child's prognosis with the physician. Perhaps the reason for this finding is that 84% of the parents reported having had discussions about the child's prognosis with the physician. Conflicts may occur between parents and health care providers over treatment and end-of-life decisions for the parents' infant or child.[16] These conflicts may be exacerbated when language and cultural differences exist between parents and health care providers. Studies[18,19] have indicated that blacks and Hispanics prefer to make decisions as a family group, whereas whites prefer autonomy in decision making. Hispanic Americans reportedly rely on physicians' judgment. Blacks reportedly hold a belief in miracles from God and are more reluctant to make end-of-life decisions.[19] However, in our sample of 78% minority parents, more than 60% of the parents made end-of-life treatment decisions for their children, and the majority of both mothers (61%) and fathers (66.7%) reported that they made the decision. In addition, we found no significant difference in agreement on cause of death by race/ethnicity or parents' participation in end-of-life decisions.

Before and after the death of an infant or a child, parents want honest, complete information delivered compassionately at a level and in language that they can understand.[7] Lannen et al[12] found that parents who are most likely to absorb information are parents without a history of depression, who have someone to share their problems with during the child's illness, who are able to express their farewells to the child in the manner they want, and who feel that information is delivered in an appropriate manner. Parents have difficulties when information is provided by staff members who speak a different language or do not understand the parents' culture.[7] Parents need information repeated, often in both verbal and written form.

The discomfort that health care providers have with death and dying, especially deaths of children, is well documented.[20] Some providers report feeling unprepared to deal with pain and symptom management,[21] and some are concerned about saving patients who "should

not be saved."[22] Others worry about becoming too involved with patients' families and having the ability to be objective affected,[23] and others report feeling unsupported when caring for dying children.[21] Years of clinical practice and training programs for health care providers can improve attitudes toward end-of-life care.[24] These experiences also may improve comfort levels in providing such care, including ongoing communication with parents during the dying process.

Follow-up meetings with the health care team can help clarify and repeat information about the cause of death and provide opportunities for parents to have their questions answered. Because communication is a 2-way process, having parents repeat what they understand is helpful so that misinformation can be corrected or further information provided. In a study of 56 parents' perspectives on physician-parent conferences after the PICU death of a child, Meert et al[25] found that only 13% of the parents had a scheduled meeting with a physician to discuss the child's death. However, 59% wanted to meet with their child's intensive care physician and were willing to return to the hospital for the meeting. Among the topics parents wanted to discuss were events leading up to the death, cause of the death, autopsy findings, and what to tell the family.

Parents often feel that reviewing medical records and autopsy findings helps them understand and clarify the reasons for the child's death.[16,20,26,27] However, many parents report difficulty in knowing how to obtain autopsy findings or how to interpret the findings when they do receive them. Meetings between parents and providers can potentially reduce parents' grief and other health risks during the long-term[28] and reinforce that all that could be done for their child was indeed done.

In summary, many parents had misconceptions about the cause of their child's death 1 month after the death, a finding that did not differ by race/ethnicity. Agreement was better for mothers when the deceased children's length of stay in the ICU was the shortest. Fathers' agreement with the chart was best when the deceased was an infant and the death was in the PICU. Talking with a physician about the infant's or child's prognosis, participating in decision making for end-of-life care, and being with the infant or child at the time of death did not improve agreement between parents' reports and chart data.

Implications and Further Study

Around the time of death of an infant or child, parents' concentration is diminished, affecting both receiving and processing of information, making ongoing communication with parents essential. Because language and cultural differences between parents and health care providers can add to this problem, having a provider, family member, friend, or advocate present from the same cultural group who speaks the same language as the parents may reduce misperceptions about cause of death. Research is needed on ways to alleviate parents' misconceptions about cause of death. Studies on types, methods, and timing of communication with parents at the time of death of an infant or a child are needed.

Acknowledgments

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Table 1

Characteristics of the parents

	No. (%) of parents[a]		
Characteristic	**Total (N = 230)**	**Mothers (n = 162)**	**Fathers (n = 68)**
Age, mean (SD), y		31.7 (7.8)	37.3 (8.6)
Race/ethnicity			
Black, non-Hispanic	82 (36)	64 (40)	18 (26)
White, non-Hispanic	50 (22)	32 (20)	18 (26)
Hispanic	98 (42)	66 (41)	32 (47)
Education	(n = 229)	(n = 161)	
< High school	30 (13)	19 (12)	11 (16)
High school graduate	56 (24)	45 (28)	11 (16)
Some college or vocational-technical training	81 (35)	58 (36)	23 (34)
College degree	62 (27)	39 (24)	23 (34)
Partnered	183 (80)	124 (77)	59 (87)
Employed			
Before death	145 (63)	86 (53)	59 (87)
After death	96 (42)	56 (35)	40 (59)
Annual family income,[b] $			
< 3000–19 999	37 (34)		
20 000–49 999	31 (28)		
50 000	41 (38)		

[a]Because of rounding, not all percentages total 100.

[b]Data for 109 families; 63 families did not report their income.

Table 2

Characteristics of the deceased infants and children

Characteristic	No. (%) of children[a]			Statistics
	Total (N = 172)	PICU (n = 100)	NICU (n = 72)	
Age at death, mean (SD), months	39.4 (64.3)	66.4 (73.2)	1.8 (3.2)	$t = 7.50$, $P < .01$
Age group				$\chi^2 = 75.5$, $P < .01$
Infants (< 12 months)	104 (60)	33 (33)	71 (99)	
Preschoolers (1–5.9 years)	30 (17)	29 (29)	1 (1)	
School age (6–12.9 years)	17 (10)	17 (17)	0 (0)	
Adolescents (13–18 years)	21 (12)	21 (21)	0 (0)	
Male sex	95 (55)	51 (51)	44 (61)	$\chi^2 = 1.7$
Days in hospital, mean (SD)	35.7 (60.9)	34.8 (68.2)	37.0 (49.4)	$t = 0.25$
Days in NICU/PICU, mean (SD)	32.7 (58.4)	29.6 (64.2)	36.9 (49.4)	$t = 0.84$

Abbreviations: NICU, neonatal intensive care unit; PICU, pediatric intensive care unit.

[a]Because of rounding, not all percentages total 100.

Table 3

Categorized causes of death by chart review and recall of mothers and fathers

Cause of death	No. (%) of total[a]		
	Chart (N = 172)	Mother (n = 157)	Father (n = 67)
Respiratory	45 (26)	25 (16)	16 (24)
Infection	20 (12)	17 (11)	10 (15)
Prematurity	32 (19)	31 (20)	6 (9)
Congenital anomalies	29 (17)	15 (10)	6 (9)
Genetic disorders	2 (1)	10 (6)	5 (7)
Cancer	11 (6)	9 (6)	4 (6)
Accidents	12 (7)	22 (14)	7 (10)
Cardiac arrest	6 (3)	11 (7)	4 (6)
Complications of surgery	2 (1)	10 (6)	8 (12)
Neurological	13 (8)	7 (4)	1 (1)

[a]Because of rounding, not all percentages total 100.

Table 4

Concordance on cause of death: parent recall vs chart review[a]

Comparison	Yes	No	Similar	Statistic
Parent				NA
Mother vs chart	87 (54)	55 (34)	20 (12)	
Father vs chart	27 (40)	28 (41)	13 (19)	
Total	114 (50)	83 (36)	33 (14)	
Race/ethnicity				
Mother vs chart				$\chi^2 = 7.2$
White non-Hispanic	16 (20)	5 (10)	9 (33)	
Black non-Hispanic	29 (36)	24 (48)	10 (37)	
Hispanic	35 (44)	21 (42)	8 (30)	
Total (n = 157)	80 (51)	50 (32)	27 (17)	
Father vs chart				$\chi^2 = 0.7$
White non-Hispanic	7 (29)	5 (20)	4 (29)	
Black non-Hispanic	6 (25)	7 (28)	4 (29)	
Hispanic	11 (46)	13 (52)	6 (43)	
Total (n = 63)	24 (38)	25 (40)	14 (22)	
Unit of care				
Mother vs chart				$\chi^2 = 2.4$
NICU	34 (49)	26 (38)	9 (13)	
PICU	48 (53)	25 (27)	18 (20)	
Father vs chart				$\chi^2 = 6.8$[b]
NICU	10 (42)	13 (54)	1 (4)	
PICU	17 (39)	14 (32)	13 (30)	
Infant/child age group				
Mother vs chart				$\chi^2 = 6.2$
Infant	35 (36)	18 (18)	45 (46)	
Preschool child	8 (29)	6 (21)	14 (50)	
School-age child	5 (31)	1 (6)	10 (62)	
Adolescent	3 (17)	2 (11)	13 (72)	
Father vs chart				$\chi^2 = 15.7$[b]
Infant	20 (53)	5 (13)	13 (34)	
Preschool child	3 (25)	6 (50)	3 (25)	
School-age child	3 (43)	0 (0)	4 (57)	
Adolescent	1 (9)	3 (27)	7 (64)	
Length of stay, mean (SD)				
Mother vs chart				
In hospital	24.5 (37.8)	46.1 (79.2)	34.6 (53.4)	$F = 2.31$

Comparison	Yes	No	Similar	Statistic
In unit	21.9 (33.5)	45.6 (79.3)	26.6 (42.0)	$F = 3.13^b$
Father vs chart				
In hospital	37.3 (68.3)	43.4 (60.2)	49.1 (58.9)	$F = 0.17$
In unit	33.4 (66.9)	35.4 (50.6)	39.7 (53.0)	$F = 0.05$

Abbreviations: NA, not applicable; NICU, neonatal intensive care unit; PICU, pediatric intensive care unit.

[a] Values in second, third, and fourth columns are number (percentage), except for values for length of stay, which are mean (SD). Because of rounding, percentages may not total 100.

[b] $P < .05$.