

Parent Health and Functioning 13 Months After Infant or Child NICU/PICU Death

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KEY WORDS

child death, infant death, NICU, PICU, parent mental health, parent chronic conditions

ABBREVIATIONS

BDI—Beck Depression Inventory
DOH—Florida Department of Health
IES-R—Impact of Events Scale-Revised
PTSD—posttraumatic stress disorder
RA—research assistant

Drs Youngblut and Brooten conceptualized and designed the study, wrote the National Institutes of Health grant application, coordinated and supervised data collection and entry, drafted the initial manuscript, and revised and approved the final manuscript as submitted. Dr Youngblut also conducted the statistical analyses. Drs Cantwell, del Moral, and Totapally identified potentially eligible families, provided the families' names and contact information, critically reviewed drafts of the manuscript, and approved the final manuscript as submitted.

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WHAT'S KNOWN ON THIS SUBJECT: Research has focused on primarily white parents, months to years after their infant/child or adult child died of cancer, accidental injury, sudden infant death syndrome, or suicide. Many parents experience depression and/or posttraumatic stress disorder and greater risk for some physical health problems.



WHAT THIS STUDY ADDS: Data on hospitalizations, changes in and management of chronic conditions, complexity of medication regimens, depression, and posttraumatic stress disorder were collected over 13 months from 249 Hispanic, black, and white parents in 188 families who experienced an infant/child NICU/PICU death.

abstract



BACKGROUND: After a child's death, parents may experience depression, posttraumatic stress disorder (PTSD), and increased risk for cancers, diabetes, psychiatric hospitalization, and suicide. Racial/ethnic differences are unknown. This longitudinal study investigated health and functioning of Hispanic, black, and white parents through 13 months after NICU/PICU death.

METHODS: Parents (176 mothers, 73 fathers) of 188 deceased infants/children were recruited from 4 NICUs, 4 PICUs, and state death certificates 2 to 3 weeks after death. Deaths occurred after limiting treatment/withdrawing life support (57%), unsuccessful resuscitation (32%), or brain death (11%). Data on parent physical health (hospitalizations, chronic illness), mental health (depression, PTSD, alcohol use), and functioning (partner status, employment) were collected in the home at 1, 3, 6, and 13 months after death.

RESULTS: Mean age for mothers was 32 ± 8 , fathers 37 ± 9 ; 79% were Hispanic or black. Thirteen months after infant/child death, 72% of parents remained partnered, 2 mothers had newly diagnosed cancer, alcohol consumption was below problem drinking levels, parents had 98 hospitalizations (29% stress related) and 132 newly diagnosed chronic health conditions, 35% of mothers and 24% of fathers had clinical depression, and 35% of mothers and 30% of fathers had clinical PTSD. At 6 months after infant/child death, 1 mother attempted suicide. Week 1 after infant/child death, 9% of mothers and 32% of fathers returned to employment; 7 parents took no time off. More Hispanic and black mothers than white mothers had moderate/severe depression at 6 months after infant/child death and PTSD at every time point.

CONCLUSIONS: Parents, especially minority mothers, have negative physical and mental health outcomes during the first year after NICU/PICU death. *Pediatrics* 2013;132:e1295–e1301

In the United States, 25 000 infants and children from birth to 19 years old die annually,^{1,2} most in a NICU or PICU.³ For parents, death of their child is a devastating life event leaving many with depression, posttraumatic stress disorder (PTSD), and increased risk for cancers, type 2 diabetes, psychiatric hospitalization, and suicide.^{4–17} Parents' stress is heightened in NICU/PICU environments by their child's appearance and behaviors,¹⁸ being separated from their child¹⁹ sometimes even at the moment of death, working relationships with health care providers,^{19,20,21} and language and cultural differences.²² Around the time of the death, parents must make stressful decisions about limiting or withdrawing life support,²³ organ donation, and disposition of the infant's/child's body.^{24,25} When wakes, funerals, and/or cremations are completed, parents must function again in their roles as spouses, parents, and employees. Some parents are able to function and move on with their lives, others are not.^{19,26}

Bereaved parents report greater use of health care services, alcohol, and prescription drugs.²⁷ Employment could be a distracter and a source of support, helping parents to recover more quickly, but little research has been done in this area.²⁷ Studies report clinical depression in as many as half of the bereaved parents that persisted for 3 years after the death.¹⁷ Mothers are more susceptible to hopelessness, depression, and psychiatric hospitalization, and fathers to heavy alcohol use.¹⁷ Bereaved parents had the highest risk of first-time psychiatric hospitalization in the first year after infant/child death and remained at risk for 5 or more years, although fathers had fewer events than mothers.⁶ However, few of these studies have focused on health outcomes for parents after a child's ICU death and racial/ethnic differences have not been studied.

Research in this area has focused on child deaths from cancer, accidental injuries, sudden infant death syndrome, and suicide in primarily white families. Research on newly diagnosed chronic conditions, changes in management of preexisting chronic conditions, and hospitalizations with a racially/ethnically diverse sample of parents is lacking. The purpose of this longitudinal study was to prospectively examine the health and functioning of Hispanic/Latino, black non-Hispanic, and white non-Hispanic parents during the first 13 months after their infant's/child's NICU/PICU death.

METHODS

Design

Using a repeated measures design, data on parent outcomes—physical health (self-rated health, hospitalizations, chronic conditions), mental health (depression, PTSD, alcohol use), and functioning (spouse/partner status, employment)—were collected at 1, 3, 6, and 13 months after infant/child death in a NICU/PICU. Data obtained from the infant's/child's hospital record included dates of birth and death, admitting diagnoses and condition, hospital and NICU/PICU lengths of stay, and mode (limiting treatment/withdrawing life support, unsuccessful resuscitation, brain death) and place of death (NICU/PICU).

Procedure

The study was approved by the institutional review boards at Florida International University, 4 South Florida hospitals, and the Florida Department of Health (DOH). The following were the inclusion criteria: parent understood spoken English or Spanish, deceased neonate from a singleton pregnancy or deceased child 18 years old or younger, and lived at least 2 hours in the NICU/PICU. Exclusion criteria were the following: deceased newborn from a

multiple-gestation pregnancy, child in foster care before hospitalization, child's injury due to suspected child abuse, parent death in the illness/injury event (eg, motor vehicle crash, childbirth).

Clinical coinvestigators at the hospitals identified Hispanic/Latino, white non-Hispanic, and black non-Hispanic parents whose infant/child died in the NICU/PICU and met study criteria. Monthly, the DOH Office of Vital Statistics electronically searched the previous month's death records for deceased infants/children (≤ 18 years) who died in a South Florida hospital and whose parent(s) were identified as Hispanic, white, or black. Research assistants (RAs) searched online databases for phone numbers for the DOH-identified families; clinical coinvestigators provided addresses and phone numbers for any missed families from their facility. After sending a letter to families identified through the hospitals and the DOH describing the study (Spanish and English), RAs called the families, determined eligibility, answered parents' questions, and scheduled the first interview, where written consent was obtained. Data were collected in the family's home from both parents whenever possible at 1, 3, 6, and 13 months after the infant's/child's death. Noncustodial parents were invited to participate if their names and contact information were provided. Data were collected in the parent's preferred language (Spanish/English) by RAs fluent in both languages. Of 752 families identified, 372 (49.5%) were not found, and 32 were not eligible. Of 348 eligible families contacted, 160 (46%) refused and 188 (54%) participated; 173 (92%) families completed the study at 13 months after infant/child death.

At 1 month, parents separately completed the demographic form (age, education, race/ethnicity, spouse/partner status, self-rated health on a scale from 1 "poor" to 10 "excellent,"

chronic conditions, hospitalizations, employment), Beck Depression Inventory (BDI),²⁸ and Impact of Events Scale-Revised (IES-R).²⁹ Parents rated the BDI's 21 items from 0 to 3. Higher summative scores indicate greater depressive symptom severity. Internal consistency coefficients ranged from 0.89 to 0.95 across time points. Based on the manual,²⁸ BDI scores were categorized as none (0–13), mild (14–19), and moderate/severe (20–63). The IES-R measures PTSD as intrusiveness of thoughts about the child, avoidance of reminders of the child, and hyperarousal. Parents rated the 22 items from 0 “not at all” to 4 “extremely.” Higher summative scores indicate greater symptom severity. Internal consistency coefficients ranged from 0.87 to 0.97 across time points. Total IES-R scores >33 were categorized as clinical PTSD.²⁹ Together, parents provided family income and description of their children. At each subsequent 1.0- to 1.5-hour visit, parents separately completed the demographic update form, BDI, and IES-R.

Data Analysis

Sample characteristics, physical health, mental health, and role functioning are described with frequencies, means, and SDs. Hypothesized group differences (unit, deceased age group, mode of death, death expected, race/ethnicity) were tested with χ^2 on categorized depression, PTSD, total number of chronic conditions, and month returned to employment; and with 1-way analysis of variance on total number of chronic conditions, self-rated health, and number of days before returning to employment. Post hoc testing used Scheffe (equal variances) and Tamhane T2 tests (unequal variances) if 3 or more groups. Analyses were conducted separately for mothers and fathers and for each time point. Statistically significant group comparisons are described.

RESULTS

Sample

The sample consisted of 176 mothers and 73 fathers (55 couples) in 188 families. Fathers were older than mothers on average (Table 1). Most mothers and fathers were Hispanic or black non-Hispanic, living with a spouse/partner, and had completed some education beyond high school. Many infants/children (57%) died after limiting treatment or withdrawing life support, 32% after unsuccessful resuscitation, and 11% after brain death.

Self-Rated Health, Hospitalizations, and Chronic Conditions

Parents' self-rated health improved between 1 and 13 months; however, at 13 months, 18% of mothers and 13% of fathers rated their health at ≤ 5 on a 10-point scale (Table 2). Black

mothers rated their health significantly better than Hispanic mothers at 1 and 6 months, but not at 3 and 13 months (Table 3). Hispanic fathers rated their health significantly better than white fathers only at 1 month ($P = .04$). Other group differences were not significant.

Hospitalizations

Fifty-six mothers (31.8%) reported 89 hospitalizations and 7 fathers (9.6%) reported 9 hospitalizations for a total of 98 parent hospitalizations during the 13 months after infant/child death. Of the 89 hospitalizations for mothers, 25 (28%) were stress-related (anxiety, depression, panic attacks, chest pain, headaches) and 29 (32.5%) were pregnancy-related (birth, miscarriage, pregnancy complications). Of the 9 hospitalizations for fathers, 3 (33%) were stress-related (anxiety, depression, cardiac problems). None of the

TABLE 1 Family, Parent, Child Characteristics

	Mothers, <i>n</i> = 176	Fathers, <i>n</i> = 73
Age, mean (SD)	32 (7.8)	37 (8.8)
Race, <i>n</i> (%)		
White non-Hispanic	34 (19)	19 (26)
Black non-Hispanic	68 (39)	19 (26)
Hispanic	74 (42)	35 (48)
Education, <i>n</i> (%)		
< High school	20 (12)	12 (16)
High school graduate	48 (28)	11 (15)
Some college	64 (37)	25 (34)
College graduate	42 (24)	25 (34)
Partnered, <i>n</i> (%)		
Yes	129 (73)	63 (86)
No	47 (27)	10 (14)
Family income, <i>n</i> (%)		
<\$20 000		59 (33)
\$20 000–50 000		57 (32)
>\$50 000		62 (35)
	NICU Deceased (<i>n</i> = 85)	PICU Deceased (<i>n</i> = 103)
Age, mo, mean (SD)	1.7 (3.1)	66.7 (72.7)
Age group, <i>n</i> (%)		
Infants (<12.5 mo)	84 (99)	34 (33)
Preschoolers (12.5–60.0 mo)	1 (1)	29 (28)
School age (60.1–144.5 mo)	0	19 (18)
Adolescents (144.51–227.0 mo)	0	21 (20)
Gender, <i>n</i> (%)		
Male	52 (61)	52 (51)
Female	33 (39)	51 (49)
Length of stay, mean (SD)		
Days in the hospital	38 (50.7)	34 (67.3)
Days in the NICU/PICU	38 (50.7)	29 (63.4)

TABLE 2 Parent Health Outcomes at 1, 3, 6, and 13 mo After Infant/Child Death

	1 Month		3 Months		6 Months		13 Months	
	Mothers	Fathers	Mothers	Fathers	Mothers	Fathers	Mothers	Fathers
Depression, <i>n</i> (%)								
None	38 (31)	21 (44)	72 (47)	38 (59)	79 (53)	43 (67)	87 (65)	42 (76)
Mild	26 (21)	8 (16)	28 (18)	11 (17)	18 (12)	10 (16)	18 (13)	5 (9)
Moderate/severe	58 (48)	19 (40)	55 (35)	16 (24)	53 (35)	11 (17)	29 (22)	8 (15)
PTSD, <i>n</i> (%)	87 (71)	34 (64)	81 (53)	30 (46)	71 (47)	31 (47)	47 (35)	16 (30)
Depression with PTSD	72 (61)	24 (51)	67 (43)	21 (32)	55 (37)	17 (26)	33 (25)	11 (20)
Self-rated health								
Mean (SD)	7.0 (2.43)	8.2 (1.76)	7.1 (2.34)	8.0 (1.65)	7.2 (2.32)	7.9 (1.79)	7.6 (2.08)	7.8 (1.74)
Rating <5, <i>n</i> (%)	41 (32)	6 (11)	37 (24)	6 (9)	39 (26)	8 (12)	24 (18)	7 (13)
Hospitalizations								
Total	10	1	15	2	20	2	44	4
Stress-related, <i>n</i> (%)	3 (30)	0	7 (47)	1 (50)	4 (20)	0	9 (20)	2 (50)
Newly diagnosed chronic conditions, ^a <i>n</i> (%)	47 (48)	4 (12)	16 (16)	7 (21)	23 (23)	11 (32)	12 (12)	12 (35)

^a Total numbers of newly diagnosed chronic conditions are 98 for mothers and 34 for fathers.

TABLE 3 Mothers' Health Outcomes by Race/Ethnicity

Mothers	1 Month			3 Months			6 Months			13 Months		
	Hispanic	Black	White	Hispanic	Black	White	Hispanic	Black	White	Hispanic	Black	White
Depression, <i>n</i> (%)												
None	13 (24)	18 (41)	7 (29)	29 (48)	28 (44)	15 (49)	26 (46)	36 (58)	17 (55)	28 (56)	36 (67)	23 (77)
Mild	14 (26)	6 (14)	6 (25)	7 (11)	15 (24)	6 (19)	3 (5)	7 (11)	8 (26)	10 (20)	6 (11)	2 (7)
Moderate/severe	27 (50)	20 (45)	11 (46)	25 (41)	20 (32)	10 (32)	28 (49)	19 (31)	6 (19)	12 (24)	12 (22)	5 (16)
<i>P</i> value		.54			.29			.03*			.57	
PTSD, <i>n</i> (%)												
Yes	44 (82)	30 (70)	11 (46)	36 (59)	36 (57)	9 (29)	32 (54)	31 (50)	8 (26)	25 (48)	19 (36)	3 (10)
No	10 (19)	13 (30)	13 (54)	25 (41)	27 (43)	22 (71)	27 (46)	31 (50)	23 (74)	27 (52)	34 (64)	27 (90)
<i>P</i> value		.04*			.02*			.03*			.002**	
Self-rated health												
Mean (SD)	6.4 (2.6) ^a	7.7 (2.2) ^a	7.1 (2.1)	6.8 (2.5)	7.2 (2.4)	7.4 (2.0)	6.6 (2.6) ^a	7.7 (2.1) ^a	7.3 (2.0)	7.4 (2.3)	7.8 (1.8)	7.4 (2.1)
<i>P</i> value		.03*			.49			.02*			.54	
Rating ≤5, <i>n</i> (%)	22 (37)	12 (26)	7 (28)	17 (27)	13 (21)	7 (23)	21 (36)	12 (20)	6 (19)	10 (19)	8 (15)	6 (20)

^a Significantly different pairs.

* *P* < .05.

** *P* < .01.

groups differed significantly in numbers of hospitalizations.

Chronic Health Conditions

Chronic health conditions increased from 108 before to 240 after the infant's/child's death with 132 newly diagnosed conditions (Table 4). Mothers reported 98 newly diagnosed chronic conditions, primarily mental illness (generally depression) followed by angina, hypertension, arthritis, and asthma. Two mothers were newly diagnosed with cancer: 1 with cervical cancer, 1 with ovarian cancer. Mothers reported the greatest number of chronic conditions at 1 month with a slight increase at 6

months due mainly to mental illness and angina (Table 2). Fathers reported 34 newly diagnosed chronic conditions, most for mental illness (generally depression) followed by hypertension and angina (Table 4). Total numbers of chronic conditions were significantly higher for mothers of deceased adolescents older than 12 years (mean = 2.06, SD = 1.51) than for mothers of deceased infants <13 months old (mean = 0.86, SD = 1.07) and deceased preschoolers, 13 months to 5 years old (mean = 1.0, SD = 1.19), *P* = .001, on post hoc Scheffe testing. Mothers who expected their child's death had fewer total chronic conditions (mean = 0.82,

SD = 1.10) than mothers who did not expect it (mean = 1.20, SD = 1.25), *P* = .04.

Parents experienced medication changes for chronic conditions during the 13 months after the death. Most of the mothers' changes were in psychotropic medications (81% increased dose, or added or switched medications) and cardiac medications (70% increased dose, or added or switched medications). Mothers reported increased doses and/or added medications for their diabetes, angina, and asthma. Fathers' psychotropic medications also changed (83% increased dose, or added or switched medications)

TABLE 4 Parents' Chronic Conditions

Chronic Conditions	Number Diagnosed		When Condition Diagnosed			
			Mothers		Fathers	
	Mothers, <i>n</i> = 176	Fathers, <i>n</i> = 73	Before Death	After Death	Before Death	After Death
No. of conditions	183	57	85 (46)	98 (54)	23 (40)	34 (60)
Mental illness, <i>n</i> = 74	56 (31)	18 (31.5)	10 (18)	46 (82)	5 (28)	13 (72)
Hypertension, <i>n</i> = 47	34 (19)	13 (22.8)	23 (68)	11 (32)	6 (46)	7 (54)
Angina, <i>n</i> = 39	33 (18)	6 (10.5)	11 (33)	22 (67)	3 (50)	3 (50)
Asthma, <i>n</i> = 29	25 (14)	4 (7.0)	19 (76)	6 (24)	2 (50)	2 (50)
Arthritis, <i>n</i> = 25	21 (11)	4 (7.0)	11 (52)	10 (48)	3 (75)	1 (25)
Diabetes, <i>n</i> = 10	8 (4)	2 (3.5)	6 (75)	2 (25)	2 (100)	0
Heart disease, <i>n</i> = 6	2 (1)	4 (7.0)	1 (50)	1 (50)	2 (50)	2 (50)
Renal disease, <i>n</i> = 5	3 (2)	2 (3.5)	3 (100)	0	0	2 (100)
Liver disease, <i>n</i> = 3	1 (0.1)	2 (3.5)	1 (100)	0	2 (100)	0
Cancer, <i>n</i> = 2	2 (1)	0	0	2 (100)	0	0
Emphysema, <i>n</i> = 1	0	1 (1.7)	0	0	0	1 (100)

Values are in *n* (%).

during the 13 months after infant/child death.

Depression and PTSD

At 6 months after infant/child death, 1 mother attempted suicide. The percentage of mothers and fathers with clinical depression and PTSD decreased between 1 and 13 months after infant/child death (Table 2); however, 35% of mothers and 24% of fathers remained depressed at 13 months with 22% of mothers and 15% of fathers reporting moderate to severe symptoms. At 6 months after infant/child death, significantly more Hispanic mothers had moderate/severe depression than white mothers, who had more mild depression. Racial/ethnic differences in depressive symptoms were not significant for mothers at 1, 3, and 13 months (Table 3) and for fathers at any time point. Mothers of deceased preschoolers and adolescents were more likely to have depression at 6 and 13 months, $P = .004$ and $P = .005$, respectively. Mothers also were more likely to have depression at 13 months if their child had brain death, $P = .05$. Fathers in the NICU group were more likely to have mild depression than fathers in the PICU group at 1 month after infant/child death, $P = .007$. The percentage of mothers and fathers with PTSD also decreased from 1 to 13

months, but at 13 months, 35% of mothers and 30% of fathers had clinical PTSD (Table 2). More Hispanic mothers had PTSD than white mothers at each time point. In addition, more black mothers had PTSD than white mothers at 3 months after infant/child death (Table 3). The proportion of fathers with PTSD did not differ by race/ethnicity at any time point. Mothers were more likely to have PTSD at 13 months if the deceased was not an infant, $P = .001$ or had brain death, $P = .01$. Despite these levels of depression and PTSD, only 11% to 19% of parents reported being in counseling or therapy.

Although fathers consumed more alcohol than mothers after infant/child death, the alcohol consumption was in the "safe range."³⁰ At 1 month after infant/child death, 19% of fathers consumed more than 4 drinks per week compared with 2% of mothers; by 13 months percentages dropped to 7% for fathers and remained at 2% for mothers.

Functioning

Most parents (72.3%) were partnered at 1 and 13 months after infant/child death. Of the 176 mothers, 17.6% had a subsequent pregnancy by 13 months after the infant's/child's death. Most pregnancies occurred in the first 6 months after infant/child death. A total

of 120 mothers and 68 fathers were employed at the time of the infant's/child's death. Return to employment ranged from 0 to 427 days (median = 32.5) for mothers and from 0 to 420 days (median = 14.0) for fathers; 3 mothers and 4 fathers reported taking no time off work after the death. Half of mothers and 74% of fathers returned to employment by the end of the first month; 9% of mothers and 32% of fathers in the first week, and 21% of mothers and 59% of fathers by the end of the second week. Mothers in the PICU group were more likely to return to employment within 1 month (0–30 days), and mothers in the NICU group between 1 and 3 months (31–91 days), $P = .05$.

DISCUSSION

The few studies on health effects for parents after the death of an infant/child have a number of limitations, as noted by Hendrickson,³¹ including retrospective designs conducted on primarily white parents of children who died of cancer, accidental injuries, sudden infant death syndrome, suicide, and miscarriage/stillbirth. Studies of parent grief, depression, PTSD, and suicide have wide variability in time after infant/child death (months to decades), age of the "child" (fetus to adult),³¹ and place of death (generally

not mentioned), often in the same sample. Parents usually have been recruited through support groups, advertisements, and organizations focused on specific causes of death or age at death. Systematic recruitment of parents soon after child death from hospitals and public death records with data collection at standardized times is rare. Other studies use large national databases assembled through mandatory reports to examine parent risk of suicide, psychiatric hospitalization, myocardial infarction, and cancers^{5–7,10,11}; however, they usually do not have information about the parent's life events in the interim. Our study addresses these limitations by controlling for time since the infant's/child's death and age at death in the design. In addition, our study's sample was largely minority and included both mothers and fathers, important factors in investigating health outcomes in an increasingly diverse US population. Our study reports research on newly diagnosed chronic conditions, changes in management of preexisting chronic conditions, and hospitalizations with a racially/ethnically diverse sample of parents, data that are currently lacking.

Our findings that depression and PTSD persist for a third of parents are consistent with the research of others¹⁷; however, our findings show that parents of a deceased preschooler, school-age child, or adolescent are more likely to be affected. The reported increased alcohol consumption in fathers did not occur in our study. Having 2 mothers with newly diagnosed cancer and 1 who attempted suicide at 6 months after child death is consistent with research using large national databases. However, the 98 hospitalizations (28% stress-related) and 132 newly diagnosed chronic conditions, more than double the number of parent chronic conditions before child death, in this

racially/ethnically diverse sample of relatively young parents have not been reported previously. More than 80% of parents required higher doses or more complex medication regimens to control chronic conditions. These findings provide strong evidence of the negative health effects that an infant's/child's death holds for parents over the first year after infant/child death.

Simon and colleagues³² reported that 60% of parents in their 60s who lost a child up to 20 years ago had poorer health-related quality of life than a comparison group, and no differences between mothers and fathers. Their findings also suggested that marital closeness may be a significant predictor of better health for bereaved couples, especially those with infant loss. Our findings may underestimate the negative health effects, as 72% of parents in our study remained married or partnered over the 13 months after infant/child death.

Death of a loved one results in an estimated \$37.5 billion annually in lost productivity in the United States.³³ In addition to anxiety and depression, unmeasured costs of grief include burn-out, irritability, substance abuse, overeating, and obesity, as well as loss prevention and management of the grieving person's health.³⁴ In our study, 120 mothers and 68 fathers were employed at the time of the infant's/child's death, with 7 parents taking no time off work after the death and 50% of mothers and 74% of fathers returning to employment by the end of the first month. As Pawlecki³⁴ notes, employed parents are trying to balance caring for other family members, the household, and their jobs. During the child's life-threatening condition, travel to distant medical centers interferes with work responsibilities. After the death, parents' sadness, anger, decreased concentration and decision-making, sleep disturbances, and fatigue

can affect relationships and work performance, including increased physical injuries. In our study, fathers reported muscle pulls and strains after the infant's/child's death. Additionally, Dussel and colleagues²⁷ reported financial effects. In their study, 60% of parents lost 10% of their annual income and 16% dropped below the poverty level after a child's death. In our study, more mothers who were not employed before the child's death became employed afterward.

In this study, few differences in parent outcomes by mode or place (NICU/PICU) of death, and whether parents expected the death were statistically significant. However, parents of preschoolers through adolescents and minority mothers often reported greater negative effects of the child's death.

Our study has some limitations. Our response rate was 54%. Many of the families who did not participate said they were not ready to talk about the death and thus our findings may be an underestimate of the negative effects on parents' health. Our sample was 79% minority, relatively well educated, and 35% with incomes of \geq \$50 000. However, the sample reflects the geographic communities from which the sample was drawn. It is not known if our findings would hold in samples with different characteristics from different geographic locations.

CONCLUSIONS

Our study findings provide important insight into parents' physical and mental health during the first year after the NICU/PICU death of an infant/child. Parents reported 98 hospitalizations, a twofold increase in chronic conditions, and increased doses or complexity of medication regimens, as well as clinical depression and PTSD in approximately one-third of parents by 13 months after infant/child death. The child's death severs parents' contact with NICU/PICU

health care providers. Given this study's findings, the concerns they raise, and the uncertainty of long-term health effects, bereavement and primary care providers

can anticipate negative health effects for parents, both physically and mentally, through at least the first year after the infant's/child's death.

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