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Parents' Acute Illnesses, Hospitalizations, and Medication Changes During the Difficult First Year After Infant or Child NICU/PICU Death

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Abstract

Background and Objectives—Infant/child death is described as a most stressful life event; however, there are few reports of effects on parent physical health during the first year after the death. The study's purpose is to examine the patterns of parent acute illnesses, hospitalizations, and medication changes over 1 to 13 months after neonatal intensive care unit (NICU) or pediatric intensive care unit (PICU) infant/child death in 3 racial/ethnic groups.

Methods—Secondary analyses were conducted with longitudinal data on parent health and functioning 1 to 13 months after infant/child NICU/PICU death. Parents (176 mothers, 73 fathers; 44% Hispanic, 35% black non-Hispanic, and 21% white non-Hispanic) of deceased infants/children were recruited from 4 children's hospitals and state death records. Inclusion criteria—parents understood English or Spanish and had a deceased neonate/child ≥ 18 . Exclusion criteria—deceased newborn from multiple gestation pregnancy, child in foster care, child's injury due to suspected abuse, or parent death in illness/injury event. Parents reported numbers and types of acute illnesses, hospitalizations, and medication changes 1 to 13 months postdeath.

Results—Parents' acute illnesses, hospitalizations, and medication changes were greatest between months 1 and 6, with relative quiescence in months 7 to 10, and an increase in months 11 to 13. Mothers (aged 32 ± 7.8 years) reported 300 acute illnesses (primarily colds/flu, headaches, anxiety/depression, and infections) and 89 hospitalizations (primarily infections, chest pain, and gastrointestinal problems). Fathers (aged 37 ± 8.8 years) reported 104 acute illnesses (colds/flu and headaches) and 9 hospitalizations.

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Declaration of Conflicting Interests

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Conclusion—After infant/child NICU/PICU death, mothers had greater morbidity than fathers, with no significant differences by race/ethnicity. Parents' health needs to be monitored in months 1 to 6 and months 11 to 13, and interventions targeted to parents in these months.

Keywords

infant death; child death; bereaved parents; parents' acute illnesses; NICU death; PICU death; parents' hospitalizations

Introduction

Death of an infant or child has been described as the most stressful of all life events.¹ Parents' grief, depression, posttraumatic stress disorder (PTSD), and psychiatric hospitalization²⁻⁶ are well documented, whereas effects on physical health are not.⁷ Bereavement research has found immune imbalance, cortisol response, altered sleep, inflammatory cell mobilization, and hemodynamic changes in heart rate and blood pressure following loss of a loved one.^{8,9} However, this research has been in elders with little in parents following infant/child loss.

Parent morbidity after child death has been studied in large national Scandinavian data sets years after the child's death^{4,5,9} and recently in 1 longitudinal US study.¹⁰ Results show increased cancers,¹¹ diabetes,¹² myocardial infarctions,¹³ newly diagnosed chronic conditions, hospitalizations, and many needed changes in medications.¹⁰ With the exception of the US study,¹⁰ most studies are cross sectional, retrospective, with mainly white samples and differing periods of time from the child's death to time of data collection.⁷ Parent's monthly morbidity data over the first year after the infant's/ child's death have not been reported but are essential for developing timing, type, and duration of interventions to maintain or improve parents' health after infant/child death. This study's purpose was to examine the monthly pattern of acute illnesses, hospitalizations, and changes to medications over 13 months after the neonatal intensive care unit (NICU) or pediatric intensive care unit (PICU) death of an infant or child in 3 racial/ ethnic parent groups.

Parent Health After Child Loss

Half of the 57 000 annual US infant and child deaths¹⁴ occur in hospitals,¹⁴ most in fast-paced intensive care units¹⁵ with high-noise levels and extensive equipment, imposing additional stress on parents' mental and physical health.^{16,17} In 1 study of parents (mean age: 32 for mothers, 37 for fathers), the number of chronic health conditions doubled by 13 months after their child's death; medication changes were necessary to manage parents' chronic conditions. There were 98 hospitalizations, 29% stress related. About 30% of these parents continued to have symptoms of depression and PTSD at 13 months postdeath.¹⁰

In cross-sectional studies from large national data sets, bereaved parents were found to be at greater risk of myocardial infarction,¹³ multiple sclerosis,¹⁸ diabetes,¹² alcoholism,¹⁹ suicide,²⁰ psychiatric hospitalization,⁴ cancer,^{11,21} and death.^{22,23} Mothers are usually more affected than fathers.¹⁹ Li and team⁴ found bereaved mothers had higher risk of psychiatric hospitalization than fathers. Mothers' risk was the highest during the first year after the

child's death and remained elevated for 5 years or more after the death. Wilcox and team²⁴ found parents of children who died of suicide and accidents had more than a 10-fold risk of psychiatric illness over parents with living children, findings similar to those of others.⁵ Bolton and colleagues²⁵ found the risk of depression among bereaved parents almost tripled during the 2 years after a child's motor vehicle death.

Li and colleagues²⁶ found bereaved parents had higher risk of first and of fatal myocardial infarction 7 to 17 years after the child's death, with higher risk for those who lost their child unexpectedly. The team also found bereaved parents had an increased risk of multiple sclerosis; parents who lost their child unexpectedly were at greater risk than those who expected the loss.¹⁸ Fang and colleagues²¹ found parents who lost a child to be at high risk for cancers associated with human papilloma virus infection (cervical, liver, and stomach). This risk remained for 5 years after the child's death. Others found significantly elevated risk for pancreatic cancer in women but not men during the first 5 years after child loss.²⁷

Espinosa and Evans²² found evidence of heightened maternal mortality in the first 2 years after child death but no differences based on mother's education, marital status, family size, child's gender, or cause of death. Others have found no increased parent mortality risk based on child's gender.¹⁹ Rostila and team²⁸ found the risk of mothers' mortality increased 4 years after child death with fathers' risk mainly after 8 years. Overall, the risk of parent morbidity and mortality appears to be greatest in the first 1 to 2 years after the death but may continue for 5 or more years after the child's death.^{4,22,25} Many of these studies, based on national databases, are retrospective finding correlations many years after the infant's/child's death. Data on parent morbidity in the difficult first year following infant/child death are lacking, especially for minority parents.

Methods

Design

This secondary analysis is a part of a longitudinal study conducted from 2006 through 2012 examining parent mental and physical health and family functioning 1 to 13 months after infant/child NICU/PICU death. Data on parent mental and physical health at 1, 3, 6, and 13 months after infant/child death were reported previously.¹⁰ Data for this secondary analysis were collected retrospectively by month from the parent interview files at 1, 3, 6, and 13 months. The present study includes never-reported data on the monthly pattern of parents' acute illnesses, hospitalizations, and medication changes over the 1 to 13 months after infant/child death.

Procedure

The study was approved by the university's and each study site's institutional review board. Parents (white non-Hispanic, black non-Hispanic, and Hispanic/Latino) whose infant or child died in an NICU/PICU were recruited from 4 South Florida children's hospitals and death records from the Florida Department of Health's (DOH) Office of Vital Statistics. Inclusion criteria—Parents were eligible for the study if they understood spoken English or Spanish, had a deceased neonate from a singleton pregnancy or deceased child 18 years,

who lived at least 2 hours in NICU/PICU. Exclusion criteria—Parents were not eligible for the study if their deceased newborn was from a multiple gestation pregnancy, deceased child was in foster care before hospitalization, child's injury was due to suspected child abuse, or a parent died in the illness/injury event.

Hospital clinical coinvestigators provided contact information of parents whose infant/child died in their NICU/PICU and met study criteria. Monthly, the Florida DOH's 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) self-identified as Hispanic, white non-Hispanic, or black non-Hispanic. 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.

A letter was sent to each family (in Spanish and English) describing the study. Bilingual RAs (fluent in Spanish and English) called families, screened for inclusion and exclusion criteria, described the study in Spanish or English, answered parents' questions, obtained verbal consent, and scheduled the first interview where written consent was obtained. Research assistants collected data from both parents whenever possible in the family's home 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. 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.

Measures

At 1 month, parents separately provided demographic information including age, education, self-identified race and ethnicity, marital/partner status, employment, and income. In response to open-ended questions at each time point, parents reported the date and type of acute illnesses; date, length of stay, and reasons for hospitalizations; and changes in medications (type of medication, dose, and type of change). These data were recorded providing a monthly pattern of parent morbidity.

Data Analysis

All analyses were done separately for mothers and fathers to avoid dependencies in the data. Frequencies of mothers' and fathers' acute illnesses, hospitalizations, and medication changes were examined monthly for each of the 13 months. Racial/ethnic differences were tested with oneway analysis of variance (ANOVA) with Scheffe (equal variances) or Tamhane (unequal variances) tests for post hoc comparisons.

Results

Sample

Parents (176 mothers and 73 fathers) were aged 18 to 58 years (76% between 18 and 40 years). Mean age was 32 ± 7.8 years for mothers and 37 ± 8.8 years for fathers. Most were Hispanic (74 mothers and 35 fathers) or black non-Hispanic (68 mothers and 19 fathers),

high school graduates (154 mothers and 61 fathers), and partnered (129 mothers and 63 fathers). Annual income was <US\$20 000 for 33% and >US\$50 000 for 35% of the families.

Of the 188 deceased children, 55% were male, 63% were infants, and 55% died in PICU. Mean hospital stay was 35.6 ± 60.41 days, ranging from <1 to 420 days. Most died after life support was withdrawn (27%), or treatment was limited (30%); 32% died after unsuccessful resuscitation, and 11% were declared brain dead. Most parents (58%) did not expect their child's death.

Parent Acute Illnesses

In the 1 to 13 months after infant/child death, parents reported a total of 404 acute illnesses. Mothers ($n = 107$, 61%) reported 300 acute illnesses (Tables 1 and 2); 77 (26%) occurred in month 1 with colds/flu and headaches most frequent, a total of 229 (76%) illnesses by 6 months. Most frequent were colds/ flu, headaches, anxiety, infections, depression, and angina. Very few illnesses occurred between 7 and 10 months, but the number increased again in months 11 through 13 with colds/ flu, headaches, and infections as most frequent.

Fathers' acute illnesses followed a monthly pattern similar to the mothers' pattern but with lower frequency (Tables 1 and 2). Fathers ($n = 46$, 63%) had a total of 104 acute illnesses with 18 (17%) at 1 month and 73 (70%) total illnesses by 6 months, mainly colds/flu and headaches. Fathers also had very few illnesses from 7 to 10 months; the number of illnesses increased slightly in months 11 through 13, mainly colds/flu and headaches.

Hospitalizations

Parents reported a total of 98 hospitalizations 1 to 13 months after the death (Table 3). Fifty-six (32%) mothers had 89 hospitalizations. The greatest number ($n = 18$, 20%) occurred in month 1, primarily due to anxiety/panic, chest pain, and surgery. By 6 months, mothers had reported a total of 54 (61%) hospitalizations, primarily for infections, anxiety, gastrointestinal problems, and chest pains comprising most frequent reasons. From 7 to 10 months, the number of hospitalizations remained low with an increase in months 12 and 13 for childbirth/childbirth complications and chest pain.

Seven (78%) fathers had a total of 9 hospitalizations—5 (55%) by 6 months, 2 from 7 to 10 months, and 1 each in months 12 and 13. Reasons for hospitalizations varied. The most frequent reasons for mothers' and fathers' hospitalizations are presented in Table 3.

Medication Changes

Mothers ($n = 41$) reported 76 changes in their medications—31 (41%) by 3 months and 51 (67%) total by 6 months after the death. From 7 to 11 months, the number of medication changes remained low with an additional increase in months 12 and 13 (Table 1). Eight fathers had a total of 17 medication changes with a total of 8 (50%) by 6 months. Fathers also had an increase of 5 (31%) changes in month 12 and 2 (13%) in month 13. Five mothers and 1 father reported medication changes for 2 different chronic conditions; 2 mothers and 1 father had medication changes for 3 different chronic conditions. Most parent-reported

changes were medications added (38% mothers and 50% fathers) or dose increases (22% mothers and 25% fathers).

Monthly Changes by Race/Ethnicity

Patterns of acute illnesses for mothers and fathers by racial/ ethnic group (white non-Hispanic, black non-Hispanic, and Hispanic) were similar to that seen in the overall group of mothers and fathers. The greatest number of acute illnesses and hospitalizations in each group occurred in month 1 and the majority by month 6, a period of quiescence in months 7 to 10 and increases again in months 11 to 13 (Table 4). Differences in number of acute illnesses, hospitalizations, and medication changes for mothers and illnesses for fathers at 1 month through 6 months and through 13 months were not statistically significant across racial/ethnic groups with oneway ANOVA. Fathers' hospitalizations and medication changes across racial/ ethnic groups were not tested because of the small number of fathers who experienced these events.

Discussion

With the exception of our earlier report on parent mental and physical health at 1, 3, 6, and 13 months after the NICU/PICU death of an infant/child,¹⁰ there is a dearth of research describing parents' physical health in the first 13 months after infant/ child death. In our earlier report, data were aggregated between time points, providing an incomplete pattern of parent morbidity. Most other research on health effects after child loss has examined parent mental health and mortality. The few studies examining parent physical health were conducted 1 to 5 or more years after child death with national data sets, mainly from Scandinavia.^{4,5,9} These studies have been retrospective, with largely white parent samples and child age at death varying from 2 months to 25 years in the same sample. They provide little guidance for timing and specific types of interventions needed to prevent morbidity and promote health in parents in the first year after an infant/child death.

This study's data provide a monthly pattern of parent morbidity over the first year after infant/child NICU/PICU death in a South Florida sample of 176 mothers with a mean age of 32 years and 73 fathers with a mean age of 37. Data provide indirect evidence of the immune, neuroendocrine, and hemo-dynamic changes that occur in parents following the death of an infant or child. Parents' pattern of morbidity demonstrates increases in acute illnesses and hospitalizations in the first month after the death and a continuing increase over the first 6 months, a period of quiescence from months 7 to 10 and an increase again in months 11 to 13 after the death. Hispanic and/ or black non-Hispanic parents reported more illnesses in the higher frequency months than white non-Hispanic parents, but these differences were not statistically significant. Many cultures and/or religions hold special events at 1 and 12 months after a child's death in which parents and family revisit the events surrounding and following the death.²⁹ Finding more illnesses and hospitalizations from 11 to 13 months supports the expected increase in parent distress around the anniversary of the child's death, although for many parents the distress lingers for years. Murphy and colleagues³⁰ found 70% of the 173 bereaved parents in their study reported that it took 3 to 4 years to put their child's death into perspective and continue with their own lives. The

child's cause of death, however, did not significantly influence parents' sense of timing in this regard.

Parents reported more illnesses in the first month after the child's death than in any other month. Higher morbidity continued through the first 6 months when 77% of the mothers' 300 acute illnesses and 68% of the fathers' 104 acute illnesses occurred. Many of the parents' illnesses were colds/flu (32%), headaches (11%), allergic reactions, and other infections (9%), suggestive of effects on their immune systems. Other acute illnesses included anxiety (9%), depression (5%), chest pains (4%), asthma attacks, shortness of breath, allergies, weakness and fainting, gastrointestinal problems, muscle spasms, kidney problems, and gall stones; these conditions suggest effects on the neuroendocrine and hemodynamic systems. The frequency and type of acute illnesses are surprising given the parents' ages, and the preponderance of colds/flu among parents living in the subtropical weather in South Florida. In Florida, only flu outbreaks are reportable, not individual episodes of flu. During the years of data collection, South Florida had mild to no flu outbreaks.³¹

Mothers' 89 hospitalizations followed a pattern similar to that of parents' acute illnesses. More than half (61%) of the hospitalizations occurred within the first 6 months of the death. The greatest number of hospitalizations for morbidity was for infections (11%), chest pain (11%), gastrointestinal problems (11%), anxiety (8%), surgery (7%), unstable blood pressure (7%), and gynecologic problems (6%). There were 20 hospitalizations (22%) for childbirth and childbirth complications. Many of these parents acknowledged great stress associated with a subsequent pregnancy³² and fear of experiencing another loss.

The numbers of acute illnesses and the need for higher doses or additional medications in bereaved parents may be the result of altered physiology under the stress of child loss. Bereavement is a significant modulator of immune cell gene expression, genes involved in innate antiviral responses.⁹ The downregulation of these genes is consistent with increased vulnerability to infectious diseases in bereaved older adults where this body of research has been concentrated. The presence of altered physiology could further increase health risk. Buckley and team⁸ note that simple preventive measures such as frequent hand washing could reduce the risk of acquiring infections, especially during early bereavement where immune imbalance appears most prevalent.

Limitations

In this heavily minority sample, most parents were educated and partnered, and 35% had an annual income over US\$50 000. Fewer fathers participated than mothers. Data on parent morbidity were from self-report with the limitations of self-report. It is not clear if findings would hold with a greater white, less educated, and poorer sample.

Conclusion

Infant/child NICU/PICU death is very stressful for parents with potential effects on their immune and cardiovascular systems. Although much research attention has focused on bereaved parents' mental health, patterns of acute illnesses and hospitalizations have not

been studied. These acute illnesses and hospitalizations affect the parent's daily functioning—going to their jobs and caring for their other children—and may exacerbate or prolong the depression and anxiety often reported. Interventions focused on preventing illnesses and promoting physical and mental health for parents who have lost an infant/child are best targeted in months 1 to 6 and 11 to 13 after the child's death.

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Table 1 Mothers' and Fathers' Acute Illnesses, Hospitalizations, and Medication Changes 1 to 13 Months After Infant/Child Death.

	1 Month	2 Months	3 Months	4 Months	5 Months	6 Months	7 Months	8 Months	9 Months	10 Months	11 Months	12 Months	13 Months	Total
Mothers (n = 176)														
Acute illnesses	77	38	51	16	19	28	9	3	3	0	11	12	33	300
Hospitalizations	18	9	7	5	9	6	1	4	1	3	10	8	8	89
Medication changes	6	12	13	3	1	16	2	1	0	1	0	15	6	76
Fathers (n = 73)														
Acute illnesses	18	12	19	5	6	13	3	2	3	1	6	7	9	104
Hospitalizations	2	1	1	0	0	1	1	0	1	0	0	1	1	9
Medication changes	3	0	3	0	0	2	1	0	1	0	0	5	2	17

Table 2
 Mothers' and Fathers' Most Frequent Acute Illnesses 1 to 13 Months After Infant/Child Death.

	1 Month	2 Months	3 Months	4 Months	5 Months	6 Months	7 Months	8 Months	9 Months	10 Months	11 Months	12 Months	13 Months	Total
Mothers														
Colds/flu	25	14	11	7	7	7	4	2	1	-	3	4	12	97
Headache	15	3	5	-	2	1	-	-	-	-	3	-	4	33
Infections	2	3	6	-	2	4	1	-	1	-	3	4	1	27
Anxiety/panic	7	6	1	5	5	-	-	-	-	-	-	1	1	26
Depression	8	3	1	1	-	-	-	-	-	-	1	-	-	14
Chest pain	6	2	3	-	1	-	-	-	-	-	1	-	-	13
Fathers														
Colds/flu	6	4	3	4	4	7	1	-	2	-	3	4	3	41
Headache	3	1	1	1	1	1	1	1	1	1	1	2	2	17
Infections	-	2	-	-	-	-	-	-	-	-	-	1	-	3
Anxiety/panic	1	1	1	-	-	-	-	-	-	-	-	-	-	3
Chest pain	-	1	-	-	-	-	-	-	-	-	-	-	-	1
Depression	-	-	-	-	-	-	-	-	-	-	1	-	-	1

Table 3
 Mothers' and Fathers' Most Frequent Hospitalizations 1 to 13 Months After Infant/Child Death.

	1 Month	2 Months	3 Months	4 Months	5 Months	6 Months	7 Months	8 Months	9 Months	10 Months	11 Months	12 Months	13 Months	Total
Mothers' hospitalizations														
Infections	1	2	2	-	3	1	-	-	-	-	-	-	1	10
Chest pain	2	1	1	-	1	1	-	-	-	-	1	3	-	10
GI	1	1	2	1	1	1	-	1	-	1	-	1	-	10
Anxiety/panic	4	-	1	2	-	-	-	-	-	-	-	-	-	7
Surgery	2	-	-	1	1	-	-	1	1	-	-	-	-	6
BP hyper/hypo	1	-	-	-	-	1	-	1	-	1	-	-	2	6
Gynecologic	1	1	1	-	-	1	-	-	-	-	-	-	1	5
Childbirth/complications	1	1	1	-	1	1	-	1	-	-	8	2	4	20
Fathers' hospitalizations														
Muscle/back	-	-	-	-	-	1	1	-	1	-	-	-	-	3
Surgery	1	-	-	-	-	-	-	-	-	-	-	-	1	2
Anxiety	-	1	-	-	-	-	-	-	-	-	-	-	-	1
Depression	-	-	-	-	-	-	-	-	-	-	-	1	-	1
Heart problems	-	-	1	-	-	-	-	-	-	-	-	-	-	1
Allergy	1	-	-	-	-	-	-	-	-	-	-	-	-	1

Abbreviations: BP, blood pressure; GI, gastrointestinal.

Table 4

Mothers' and Fathers' Illnesses, Hospitalizations, and Medication Changes by Race/Ethnicity 1 to 13 Months After Infant/Child Death.

	1 Month	2 Months	3 Months	4 Months	5 Months	6 Months	7 Months	8 Months	9 Months	10 Months	11 Months	12 Months	13 Months	Total
Mothers, n = 176														
Illnesses	77	38	51	16	19	28	9	3	3	0	11	12	33	300
White non-Hispanic	13	6	11	2	4	8	4	3	0	0	1	2	12	66 (22%)
Black non-Hispanic	25	17	19	6	14	11	3	0	1	0	4	4	7	111 (37%)
Hispanic	39	15	21	8	1	9	2	0	2	0	6	6	14	123 (41%)
Hospitalizations	18	9	7	5	9	6	1	4	1	3	10	8	8	89
White non-Hispanic	5	0	1	0	2	0	0	1	0	0	2	3	1	15 (17%)
Black non-Hispanic	6	4	3	2	6	3	0	3	1	2	7	3	5	45 (51%)
Hispanic	7	5	3	3	1	3	1	0	0	1	1	2	2	29 (33%)
Medication changes	6	12	13	3	1	16	2	1	0	1	0	15	6	76
White non-Hispanic	4	2	3	1	0	3	2	1	0	1	0	3	0	20 (26%)
Black non-Hispanic	1	2	4	1	0	5	0	0	0	0	0	5	2	20 (26%)
Hispanic	1	8	6	1	1	8	0	0	0	0	0	7	4	36 (47%)
Fathers, n = 73														
Illnesses	18	12	19	5	6	13	3	2	3	1	6	7	9	104
White non-Hispanic	6	3	2	1	1	4	0	0	2	0	1	3	1	24 (23%)
Black non-Hispanic	1	4	5	0	1	2	0	0	0	0	2	1	3	19 (18%)
Hispanic	11	5	12	4	4	7	3	2	1	1	3	3	5	61 (59%)
Hospitalizations	2	1	1	0	0	1	1	0	1	0	0	1	1	9
White non-Hispanic	1	0	0	0	0	0	1	0	0	0	0	0	0	2 (22%)
Black non-Hispanic	1	1	0	0	0	0	0	0	0	0	0	1	1	4 (44%)
Hispanic	0	0	1	0	0	1	0	0	1	0	0	0	0	3 (33%)
Medication changes	2	0	3	0	0	2	1	0	1	0	0	5	2	16
White non-Hispanic	2	0	1	0	0	2	0	0	0	0	0	0	1	6 (38%)
Black non-Hispanic	0	0	1	0	0	0	1	0	1	0	0	4	0	7 (43%)
Hispanic	0	0	1	0	0	0	0	0	0	0	0	1	1	3 (19%)