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Black, White, and Hispanic Children's Health and Function 2-13 Months after Sibling ICU Death

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Abstract

Objective: To describe children's anxiety, depression, behaviors, and school performance at 2-13 months after sibling neonatal/pediatric intensive care unit (NICU/PICU) or emergency department (ED) death and compare these outcomes by child age, sex, race/ethnicity, whether the child saw their sibling in the NICU/PICU/ED and attended the sibling's funeral.

Study design: Children in 71 families were recruited for this longitudinal study from 4 children's hospitals and 14 other Florida hospitals. Children rated anxiety (Spence Children's

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Anxiety Scale) and depression (Children's Depression Inventory); parents rated child behaviors (Child Behavior Checklist) and reported school performance (detentions, suspensions, requested parent-teacher meetings) at 2, 4, 6, and 13 months post-sibling death. Analyses included RM-ANOVA, t-tests and oneway ANOVA.

Results: 132 children and 96 parents participated. More children were female (58%), black (50%), and school-aged (72%). 43% of children had elevated anxiety; 6% had elevated depression over 13 months post-sibling death. Child-rated anxiety was higher for girls and Black vs White children. Child-rated anxiety and depression were lower if they saw their sibling in the NICU/PICU/ED before and/or after the death, and/or attended the funeral. Teens were more withdrawn than school-age children at all time points. Children who did not see their deceased sibling in the NICU/PICU/ED after death had more requests for parent-teacher conferences.

Conclusion: Children's anxiety was more common than depression, especially in girls and Black children. Children who saw their siblings in the NICU/PICU/ED before/after death and/or attended funeral services had lower anxiety and depression over the first 13 months after sibling death.

Keywords

Child death; Sibling death; Child bereavement; Sibling bereavement

Almost 42,000 US neonates, infants, children, and adolescents die annually¹, most in Neonatal Intensive Care units (NICUs) or Pediatric Intensive Care units (PICUs)². Surviving children may have witnessed their sibling injured, in distress, in multiple hospitalizations³, and may have lost support from grieving parents, experiences that can affect children's health and functioning.^{4,5}

Following sibling death, children experience nightmares, depression, separation anxiety, fear of being alone, guilt, trouble concentrating, and sadness⁶⁻¹². Parents reported surviving children had changed behaviors, did not understand what was going on, and tried to maintain a connectedness with the deceased sibling¹³. At least 50% of children have behavior problems after a sibling's death^{4,5}, influenced by children's ages, development and understanding of death¹⁴⁻¹⁶.

School-age children may expect their deceased sibling to age, grow and develop⁸, illustrating that younger children (age<10) often do not understand death's irreversibility¹⁵. Many children are fearful that they and/or other loved ones would die^{8,9,17}. Surviving 3- to 5-year-olds reportedly have hyperactivity and trouble sleeping; 6- to 11-year-olds were sad and depressed with frequent daydreams. Teens had problems with impulsivity, hyperactivity, moodiness, worry, daydreams, nightmares, and trouble sleeping; they were poor eaters, demanding attention, refusing to talk, feeling unloved^{7,19} and had trouble returning to normal functioning,⁹ putting them at risk of untoward outcomes.

Girls are reportedly more affected by sibling loss than boys²⁰, and experience greater anxiety, depression, withdrawn behavior, thought problems, and attention-seeking; boys demonstrate inability to concentrate and hyperactivity after a sibling's death²¹. Data on children's responses to sibling loss by race/ethnicity is very limited. More Black school-age

children reported thinking about their deceased sibling at 7 and 13 months after the death and reported more fears and changes in themselves than Hispanic and White children⁸; differences in adolescents were not found⁹.

Children's responses and participation around a child's death vary across cultures, religions, race/ethnicity and the deceased's age^{22,23}. Children may not be allowed to see their sibling in the ICU²³. Some cultures prevent children from attending wakes or funerals²², although it may help them²⁴.

In summary, half of children after sibling death have problems requiring clinical intervention^{4,5}. Research to guide their care suffers from: methodological weaknesses¹¹; cross-sectional retrospective study designs^{4,6,10,20,25,26}; adults who experienced a sibling's death in childhood^{4,26}; and parents' reports about their children^{7,13,20,24}. Samples have wide age ranges of deceased siblings (newborn-30 years), time since sibling death^{4,25,26}; mainly white samples^{4,7,10,12,18,20,26} or race/ethnicity not reported^{6,24,25,27}; heavy focus on siblings of deceased children with cancer^{7,10,18,25}; and include children who lost parents or siblings in the same study^{6,21,27}. Our objective was to describe children's anxiety, depression, behaviors and school performance 2-13 months after sibling PICU/NICU/ED death and compare these outcomes by child age, sex, race/ethnicity, and whether they saw the sibling in ICU before/after death and attended the sibling's funeral.

Methods

A convenience sample of 132 children and 96 parents of 71 infants/children who died in the ICU/ED was recruited between June 2011 and December 2015 directly from 4 children's hospitals and through obituaries from 14 other Florida hospitals. All parents were age 19 or older; Hispanic, Black, or White; and understood spoken English or Spanish. **Child inclusion criteria:** 6-18 years old; English-speaking; self-identified race/ethnicity as Hispanic, Black, or White; lived with the mother during pregnancy (neonatal deaths) or sibling before the death and the same parent(s) since the death; and in age-appropriate grade in school ± 1 year. **Child exclusion criteria:** unable to participate verbally; lived in foster care before or after the death; or death of a parent or more than one sibling in the same event. Children whose self-identified race was other than Hispanic, black, or white (eg, Asian, Native American) were excluded due to low numbers in Florida.

Procedure.

The study was approved by the institutional human subjects review boards at the Principal Investigators' university and 4 Florida children's hospitals. Hospital clinical co-investigators identified Hispanic, black, and white parents whose infant/child died in the ICU/ED at their hospital and seemed to meet study criteria, and provided addresses and phone numbers for families from their facility (public information by Florida law). Research assistants (RAs) searched public online obituary notices (e.g. newspapers, funeral homes, crematoriums) to identify potentially eligible families and then online databases for available phone numbers and addresses. At 4-7 weeks after the death, identified families were sent a letter (in Spanish and English) explaining the study, identifying the project director and RAs, and providing the project phone number and email address. About 1 week after the letter was sent, an RA

(fluent in Spanish and English) called the parent(s), screened for inclusion/exclusion criteria, answered questions, and asked whether the parent(s) and their eligible children were willing to be in the study. Most parents talked with their eligible child(ren) about the study before they responded to the RA about their participation. If parents and children indicated willingness to participate, the RA made an appointment for the first data collection visit in the family's home. There, the RA again explained the study to the parent(s), answered their questions and obtained their signed informed consent for participation of their eligible children and themselves and review of their deceased child's hospital record. Noncustodial parents were invited to participate if their names and contact information were provided. After parent consent, the RA explained the study to eligible children, answered their questions, and obtained their signature on an assent form; 18-year-olds signed consent forms for their own participation. Only children who signed the assent form after their parent(s) gave consent were interviewed. Of the 281 families who received a contact letter, 224 (80%) were eligible and 71 (32%) participated. This participation rate is consistent with a systematic review of recruitment strategies in research with children with life-threatening illnesses²⁸.

At 2, 4, 6, and 13 months after the sibling's death, the RA read the items from the Spence Child Anxiety Scale – Child report version (SCAS)²⁹, Child Depression Inventory (CDI)³⁰, and the Child Demographic Form to each child privately and recorded their responses (English only – all in English-speaking schools). In English or Spanish and separated from their children, the parent(s) completed a Child Behavior Checklist (CBCL)³¹ and school performance questions for each of their participating 6- to 18-year-old children, and the parent and family demographic forms.

Measures.

Child Anxiety.—The SCAS²⁹ has 45 items that children rated from 0 “never” to 3 “always”. Children's SCAS summative scores are based on 38 items. Reliabilities in this sample were .88-.92. The SCAS was tested psychometrically as a measure of number and severity of symptoms of anxiety and clinically validated as an indicator of children who need treatment for anxiety³². As Spence recommends³², children's SCAS scores were categorized based on child age group and sex as “normal” and “elevated;” SCAS scores for “normal” were: school-age boys 39, teen boys 32, school-age girls 49, and teen girls 38³².

Child Depression.—The CDI³⁰ has 27 items at a 1st grade reading level that children rate on a 3-point scale. The CDI was tested psychometrically as a measure of severity of depressive symptoms and clinically validated as an indicator of children who need treatment for depression³⁰. Kovacs³⁰, in a large ethnically diverse normative sample, reports strong psychometric properties. Reliabilities in this sample were .76-.79. Children's CDI scores were categorized as “no depression” (scores 0-19) and “some depression” (scores 20-35)³⁰.

Child Behavior.—The 6- to 18-year-old version of the CBCL measures Internalizing (Anxiety/Depression – 13 items, Withdrawn – 8 items, & Somatic Complaints – 11 items) and Externalizing (Rule Breaking – 17 items & Aggression – 18 items) Behavior

Problems³¹. For each of their participating children, mothers and fathers rated each item from 0 “not true” to 2 “very or often true” at each time point. Reliability ranges in this study for the 5 subscales were .64-.92 for mothers and .24-.92 for fathers. Raw scores rather than domain scores were used as recommended for research³¹.

School performance.—Children rated how often in the past 2 weeks they had trouble focusing on schoolwork from 1 “Never” to 10 “All the time” at each of the four time points. For each of their participating children, parents reported the number of school detentions, school suspensions, and requests for parent-teacher conferences since the sibling’s death. For all children, this included one academic-year period and one summer period. Summative data for the first 13 months post sibling death were used to minimize effects of summer and academic year.

Demographic variables included the surviving child’s sex, age (school-age or adolescent), race/ethnicity (Hispanic, Black non-Hispanic, White non-Hispanic), whether they saw the sibling in the ICU/ED before and/or after the death and/or attended the funeral (coded as 1 “Yes” and 0 “No”).

Statistical Analyses.

Children’s total scores on the SCAS, CDI, and difficulty focusing on schoolwork, and mother- and father-rated CBCL internalizing and externalizing subscales were tested for main effects of time (2-13 months); age group, sex, and race/ethnicity (separately); and interaction effects of time with age group, sex, and race/ethnicity (separately) were tested with RM-ANOVA. Consistent with recommendations for the SCAS³², CDI³⁰ and CBCL³¹, we used raw summative scores to investigate change over time. Outcomes at each time point and aggregate school performance data were compared across groups created by the 6 demographic variables with t-tests for 2-group variables and oneway ANOVA (with post-hoc Scheffe or Tamhane tests) for the 3-group race/ethnicity variable. Categorized SCAS (normal, elevated) and CDI (none, some) scores (clinical validated for use to guide treatment^{30,32}), and dichotomous school variables were compared on the 6 demographic variables with Chi square tests. Bootstrapping (2000 “re-samples” stratified by family) was used for all analyses to account for having more than one participating child per family in 40 (56%) of the 71 families.

Results

Children (N=132), 70 mothers, and 26 fathers participated. Mean ages were 10.6 years (SD=3.43) for children, 36 (SD=7.1) for mothers, and 39 (SD=7.4) for fathers. Most children were female (n=76, 58%), black (n=67, 50%) or Hispanic (n=39, 30%), and school-aged (n=95, 72%). Most mothers were black (n=30, 43%) or Hispanic (n=23, 33%), college graduates (n=23, 33%) or with some college education (n=28, 40%), and partnered (n=54, 77%). Most fathers were black or white (n=9 each, 35% each), high school graduates (n=18, 69%), and partnered (n=24, 92%). Annual family income was <\$20,000 for 28 (39%) families; \$20,000 to \$49,999 for 26 (37%) families, and \$50,000 or more for 17 (24%) families. Most of the 71 deceased children were male (n=44, 62%), teens or infants (n=26 each, 37%), black (n=30, 42%) or Hispanic (n=23, 32%), died in a PICU (n=45, 63%) or

NICU (n=17, 24%) as a result of failed cardiopulmonary resuscitation (n=25, 35%), treatment limitation (n=21, 30%), life support withdrawn (n=10, 14%), or brain death (n=15, 21%). Causes of death included congenital/genetic anomalies, prematurity, infection, and trauma, consistent with national statistics for most common causes of death^{1,33}.

Most children (n=88, 67%) saw their sibling in the NICU/PICU/ED: 46 (52%) both before and after the death; 29 (33%) **before** the death only; and 13 (15%) **after** the death only. Most (n=106, 81%) attended their sibling's funeral. Only 13 (10%) children did not see their sibling in the ICU/ED and did not attend the funeral. Children who saw their sibling in the ICU/ED before or after the death, and attended their sibling's funeral differed significantly (Table 1). Children were most likely to see their sibling in the ICU/ED before and/or after the death if they were teens, and if the deceased sibling was at least 6 years old, died in the PICU, as a result of brain death or withdrawal of life support. Children were least likely to attend the funeral if the deceased was an infant (< 12 months of age), died in the NICU, as a result of treatment limitation.

Child-rated Anxiety.

Fifty-seven (43%) children (56% Hispanic, 48% black, 12% white) had “elevated” anxiety at least once over the 13 months after sibling death based on recommended cutoff scores³². The number of elevated anxiety scores decreased from 35 (27%) at 2 months to 15 (11%) at 13 months; three children had “elevated” anxiety scores at all 4 time points. Children's anxiety scores decreased significantly from 2 months to 4, 6, and 13 months, bootstrap RM-ANOVAs $F=7.97$, $P<.001$. Interaction effects for time by age group and sex, but not by race/ethnicity, were statistically significant. Teens had greater anxiety at 2 and 13 months, school-aged children at 4 and 6 months. Girls had significantly greater anxiety than boys at all time points, but girls had much more change in scores than boys from 2-13 months. Anxiety scores were significantly higher for Black children than White children at 2 months. Total anxiety scores did not differ by child age. Children who saw their sibling in the ICU/ED before death had significantly lower anxiety scores at all 4 time points. Those who saw their sibling in the ICU/ED after death had significantly lower anxiety scores at 2 and 6 months. Children who attended the funeral had lower anxiety scores at 6 months (Table 2).

Child-rated Depression.

Eight (6%) children (2.6% Hispanic, 6% black, 11.5% white) had “some depression” at least once over the 13 months after the sibling's death based on recommended cutoff scores³⁰. Two (3%) children had elevated depression scores from 2-6 months, and only 1 (0.8%) at 13 months. Depression scores did not change significantly over time, bootstrap RM-ANOVA $F=1.01$, $p=.39$; main effects of age group, sex, and race/ethnicity and their interaction effects by time were not statistically significant. Children had significantly lower depression scores at 4 and 6 months if they saw their sibling in the ICU/ED before death and at 6 months if they saw their sibling after death. Those who attended the funeral had significantly lower depression scores at 4 and 6 months (Table 2).

Parent-rated Child Internalizing Behaviors (Anxiety/Depression, Withdrawn Behaviors, Somatic Complaints).

Mothers' and fathers' ratings of their child's Anxiety/Depression, Withdrawn Behaviors and Somatic Complaints did not change significantly over time, bootstrap RM-ANOVA $F=0.39-1.96$, $p=.10-.75$; interaction effects of time by age group, sex, and race/ethnicity also were not significant.

Mothers rated the child as having significantly more Anxiety/Depression if they were school-aged (6, 13 months), female (2, 4, 6, 13 months), or saw their sibling in the NICU/PICU/ED after death (6 months). Mothers' ratings of Anxiety/Depression for children who went to the sibling's funeral were significantly lower at 4 and 6 months, but higher at 13 months (Table 3). Mothers' ratings did not differ significantly by child race/ethnicity and whether the child saw their sibling in the ICU/ED before death. Fathers rated the child as having significantly more Anxiety/Depression if they were female (2, 4, 6, 13 months), did not see the sibling in the ICU/ED before death (6 months), or saw their sibling after death in the ICU/ED (2, 4, 6 months) (Table 4). Fathers' ratings did not differ significantly by child age or race/ethnicity or whether the child attended the funeral.

Mothers rated children as having significantly more Withdrawn Behaviors if they were teens (2, 4, 6, 13 months), saw their sibling in the ICU/ED before death (2, 6, 13 months) or after death (2, 4, 13 months). Mothers' ratings of Withdrawn Behaviors for children who went to the sibling's funeral were significantly lower at 4 months, but higher at 13 months (Table 3). Fathers rated children as having significantly more Withdrawn Behaviors if they were teens (2, 4 months), saw their sibling in the ICU/ED before (2, 4 months) or after the death (2, 4, 6, 13 months), or did not attend the funeral (13 months) (Table 4). Mothers' and fathers' ratings did not differ significantly by child sex or race/ethnicity.

Mothers rated the child as having significantly more Somatic Complaints if they were teens (4 months), female (2, 13 months), white compared with Hispanic (6 months), or saw their sibling before or after the ICU/ED death (13 months); mothers rated the child's Somatic Complaints significantly higher at 2 months, but lower at 6 and 13 months if they did not go to the funeral (Table 3). Fathers rated the child as having significantly more Somatic Complaints if they were teens (4, 13 months), female (6, 13 months), saw the sibling in the ICU/ED before death (4 months), or did not go to the funeral (2, 6 months) (Table 4). Fathers' ratings did not differ significantly by child race/ethnicity or whether the child saw the sibling in the ICU/ED after the death.

Parent-rated Child Externalizing Behaviors (rule breaking and aggressive behaviors).

Mothers' and fathers' ratings of their children's Rule Breaking and Aggressive Behaviors did not change significantly over time, bootstrap RM-ANOVA $F=0.09-2.48$, $p=.06-.96$; interaction effects of time with age, sex, and race/ethnicity were not statistically significant.

Mothers rated their child as having significantly more Rule Breaking Behavior if they saw their sibling in the ICU/ED after death (4 months) (Table 3). Mothers' ratings did not differ significantly by the child's age, sex, and race/ethnicity, whether the child saw the sibling before their death or went to the funeral. Fathers rated their child as having significantly

more Rule Breaking Behaviors if they were school-aged (13 months), saw the sibling in the ICU/ED after the death (6 months), or did not go to the funeral (4, 6 months) (Table 4). Fathers' ratings did not differ significantly by child sex or race/ethnicity or by whether the child saw their sibling before the ICU/ED death.

Mothers' ratings of their children's Aggressive Behaviors did not differ significantly by any of the 6 demographic variables. Fathers rated the child as demonstrating significantly more Aggressive Behaviors if they were school-aged (13 months), did not see their sibling in the ICU/ED before the death (2, 4, 6, 13 months), saw their sibling after the death (2, 6 months), or did not attend the funeral (4, 6, 13 months) (Table 4). Fathers' ratings did not differ significantly by child sex or race/ethnicity.

Child School Performance.

Fourteen children had a total of 41 school detentions (range 1-9); 9 (7%) children were suspended from school a total of 28 times (range 1-7); and a total of 123 parent-teacher conferences were requested for 59 (45%) children (range 1-8) during the first 13 months after their sibling's death as reported by parents. Significantly more requests for parent-teacher conferences were made for children who did not see their deceased sibling in the ICU/ED after death ($M=1.05$, $SD=1.64$) vs those who did ($M=0.78$, $SD=1.26$), bootstrap mean difference $=.28$ ($SE=0.14$), $p=.05$. Number of detentions, suspensions, and requests for parent-teacher conferences did not differ significantly on the remaining 5 demographic variables.

Children's ratings of their trouble focusing on schoolwork did not change significantly across time, bootstrap RM-ANOVA $F=2.35$, $p=.07$; interaction effects of time with age group, sex, and race/ethnicity were not statistically significant. Boys rated focusing on schoolwork as significantly more difficult than girls at 2 months. Those who saw their sibling in the NICU/PICU/ED before or after the death had significantly less trouble focusing on schoolwork at 6 months. Trouble focusing on schoolwork did not differ significantly at any time point by whether they attended the funeral.

Discussion

A sibling's death has been reported as frightening, confusing, and lonely^{4,5}, with children having nightmares, depression, separation anxiety, panic attacks, guilt, and trouble concentrating, especially in school⁶⁻¹¹. In this study, 43% of children had elevated anxiety and 6% had some depression in the first 13 months after the sibling's death, much higher than US national data for anxiety or depression (3% each)³⁴ in 4- to 17-year-old children. Children's self-rated anxiety, but not depression, decreased significantly from 2 months to 4, 6, and 13 months after sibling death, with little change from 4 to 6 months and 6 to 13 months.

Child-rated anxiety and depression did not differ significantly between school-age children and teens, contrary to the findings of the Centers for Disease Control and Prevention (CDC)³⁴ that both anxiety and depression were more common in teens (4.1% anxiety, 5.1% depression) than school-age children (2.9% anxiety, 1.7% depression). Girls had

significantly greater anxiety than boys at all 4 time points, consistent with findings by Worden et al.²¹ Depression did not differ significantly by child sex in this study, contrary to findings by Worden et al that girls had greater depression than boys 2-13 months after sibling or parent death in a 90% white non-Hispanic sample.²¹ In large national surveys of healthy US children, the CDC³⁴ reported anxiety as more common in boys (boys 3.4%, girls 2.6%) and depression as more common in girls (boys 2.8%, girls 3.1%), in contrast to our data from children with deceased siblings.

Black non-Hispanic children in our study rated their anxiety symptoms significantly higher than White non-Hispanic children at 2 months after the death only, with no differences in depression by race/ethnicity at any time point. During the first 13 months, more Hispanic (56%) and Black non-Hispanic (48%) children had elevated anxiety scores than White non-Hispanic children (12%). More White non-Hispanic children (11.5%) had elevated depression scores than Black non-Hispanic (6% depression) and Hispanic (2.6% depression) children. In contrast, the CDC³⁴ reported that both anxiety and depression were more common in white non-Hispanic children (3.2% anxiety and depression) than Hispanic (2.6% anxiety, 2.4% depression) and black non-Hispanic children (2.2% anxiety, 2.5% depression). Other studies of racial/ethnic differences in children's anxiety and depression after losing a sibling are limited. Possible reasons for the differences in our findings include a more ethnically diverse sample than Worden et al (90% white)²¹, and a more targeted focus on children after a sibling's death, not after either a sibling's or parent's death²¹ and not on healthy non-bereaved children³⁴.

It also likely depends on whether the child or the parent is responding to the measures. Greater anxiety for girls than boys was significant for children's self-rated anxiety and for parents' rating of the child's anxiety/depression at all time points. However, sex differences in child-rated depression were not significant at any time point. Roche, Brooten, and Youngblut found mother's and father's ratings of the child's current health higher than that reported by the children.³⁵

School performance after sibling death is a concern. Boys reported more difficulty in focusing on school work than girls at 2 months, in contrast to Worden et al who reported girls having greater thought difficulties than boys 2-13 months after sibling or parent death.²¹ In our study, parents of 45% of the children reported attending at least 1 parent-teacher conference in the first 13 months after the sibling's death. Comparisons in numbers of requested parent-teacher conferences, detentions, and suspensions in our study did not differ significantly by the child's sex, age, or race/ethnicity.

Children who did not see their dying sibling in the ICU/ED before death or were unable to see the sibling's body after death rated their anxiety and depression as significantly greater than those who did see their sibling. In contrast, both mothers and fathers ratings of child anxiety/depression were higher if the child saw the sibling before or after the death. Parents rated children who saw their sibling in the ICU/ED before or after the death as being more withdrawn and having more somatic complaints and rule-breaking behaviors. As noted in other studies^{8,9,13}, seeing their dying sibling in the ICU/ED gives children time to see the sibling "person to person"⁹, to say good-bye verbally, hold the sibling's hand, or just spend

time at the bedside with their sibling. For children whose sibling died as a neonate without going home, seeing the sibling may make the sibling's existence more real and diminish fantasies children may develop about their sibling. Parents' ratings suggest that they perceived seeing the sibling before and after the death in the ICU/ED as detrimental to the children, whose self-ratings suggest the opposite.

Most children attended the funeral, despite taboos for this practice in some cultures²². Children who attended the funeral rated their anxiety lower at 6 months and their depression lower at 4 and 6 months than children who did not attend the funeral, indicating their perception of attending the funeral as beneficial. The picture with parents' perceptions is not as clear. Mothers perceived children who attended the funeral as having less withdrawn behaviors at 6 and 13 months and lower anxiety/depression at 4 months, but greater anxiety/depression at 6 months in contrast to the children's ratings. Mothers also perceived these children to have greater somatic complaints at 6 months but less at 13 months. Fathers perceived their children who attended the funeral as less withdrawn (13 months), having less somatic complaints (2 and 6 months), less rule-breaking behaviors (4 and 6 months), and less aggression (4, 6, and 13 months), suggesting that fathers also saw the child's attending the funeral as beneficial to their child's mental health. A qualitative study of children who lost a sibling or a parent,³⁶ reported that children were glad they saw the sibling at the funeral, even if they had not wanted to do so. Including the children in the preparations and/or the service seemed to help them.

The first 6 months after the sibling's death were problematic for surviving children when 85% of elevated anxiety and 91% of "some" depression occurred. A report of children's morbidity and treatments after sibling death found a similar pattern with most of the children's 207 illnesses and 674 treatments/health services occurring in the first 6 months post-sibling death and again in months 11 through 13³⁷. Perhaps this pattern reflects the activities in some cultures and religions at the 6-month post-death milestone²³. The 1-year anniversary of the death is often a very sensitive period for families; in some religions and cultures, this anniversary is marked with many activities in the child's memory^{36,37}. The first 6 months after sibling death is also when parents' pattern of morbidity has shown the greatest incidence in acute illnesses, hospitalizations, newly diagnosed chronic conditions and medication changes^{38,39}, perhaps further sensitizing children's responses. These findings reinforce the importance of the first 6 months after sibling death as a time when parents' and surviving children's physical and mental health merits monitoring and preventive interventions.

Limitations.

Our sample was more racially/ethnically diverse than most previous studies which may account for the differences in findings of studies of primarily white children. Although a limitation, the 32% response rate is not surprising as the recruitment was done at a difficult time for families, the topic of death in children is very sensitive and often taboo (even for researchers and health care providers), and we faced problems common to research with children (e.g. children who refuse to participate, parents trying to protect their child from emotions they fear may arise when answering questionnaire items). Hudson et al reported a

similar response rate in their systematic review of recruitment strategies in research with children with life-threatening illnesses.²⁸ Our study used a convenience sample rather than a randomly chosen sample. Caution should be used when interpreting the generalizability of the results and the statistical comparisons.

Children's responses to sibling death were demonstrated primarily in elevated self-rated anxiety rather than self-rated depression, with girls having more anxiety than boys; 85% of the elevated anxiety and 91% of the elevated depression occurred in the first 6 months after the sibling's death, making the first 6 months post-sibling death the optimal time for targeted interventions to support children who have lost a sibling. Facilitating children's ability to see their sibling in the NICU/PICU/ED, especially before the death, may help them with their psychological reactions in the first 13 months.

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List & Definition of Abbreviations

CBCL	Child Behavior Checklist
CDI	Children's Depression Inventory
ED	Emergency Department
ICU	includes both the neonatal and pediatric intensive care units
NICU	Neonatal Intensive Care Unit
PICU	Pediatric Intensive Care Unit
RA	Research Assistant
RM-ANOVA	Repeated Measures Analysis of Variance
SCAS	Spence Children's Anxiety Scale

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Table 1.

Significant comparisons of children who did and did not see their siblings in the ICU/ED before and after the death and who did and did not attend the funeral.

Characteristic	See in ICU/ED				Attend Funeral [‡]	
	Before Death		After Death		No (n [%])	Yes (n [%])
Full Sample (n=132)	No (n [%])	Yes (n [%])	No (n [%])	Yes (n [%])	No (n [%])	Yes (n [%])
	57 (43%)	75 (57%)	73 (55%)	59 (45%)	25 (19%)	106 (81%)
Child Age						
School-age (n=96)	47 (49%)	49 (51%)	58 (60%)	38 (40%)	21 (22%)	74 (77%)
Teen (n=36)	10 (28%)	26 (72%)	15 (42%)	21 (58%)	4 (11%)	32 (89%)
	X² = 4.79*		X² = 3.72		X² = 2.04	
Unit [‡]						
PICU (n=77)	25 (32%)	52 (68%)	30 (39%)	47 (61%)	7 (9%)	69 (91%)
NICU (n=35)	21 (60%)	14 (40%)	26 (74%)	9 (26%)	18 (51%)	17 (49%)
ED (n=20)	11 (55%)	9 (45%)	17 (85%)	3 (15%)	0 (0%)	20 (100%)
	X² = 8.78**		X² = 20.56**		X² = 33.23**	
Mode of Death [‡]						
Withdrew life support (n=15)	5 (33%)	10 (67%)	3 (20%)	12 (80%)	2 (13%)	13 (87%)
Limited treatment (n=37)	14 (38%)	23 (62%)	24 (65%)	13 (35%)	13 (36%)	23 (64%)
Brain death (n=25)	3 (12%)	22 (88%)	9 (36%)	16 (64%)	0 (0%)	25 (100%)
Failed CPR (n=47)	28 (60%)	19 (40%)	31 (66%)	16 (34%)	4 (9%)	43 (91%)
	X² = 15.97**		X² = 14.71**		X² = 18.12**	
Deceased Age [‡]						
Infant (n=56)	34 (61%)	22 (39%)	42 (75%)	14 (25%)	24 (43%)	32 (57%)
Preschool (n=7)	3 (43%)	4 (57%)	4 (57%)	3 (43%)	0 (0%)	7 (100%)
School-age (n=23)	3 (13%)	20 (87%)	9 (39%)	14 (61%)	0 (0%)	22 (100%)
Teen (n=46)	17 (37%)	29 (63%)	18 (39%)	28 (61%)	1 (2%)	45 (98%)
	X² = 16.26**		X² = 16.10**		X² = 35.85**	

* p < .05

** p < .01

[‡] n = 131;

[‡] n = number of surviving children with a deceased sibling in each category

Table 2. Significant comparisons of child-rated 2-13 month Anxiety and Depression by demographic variables.

Outcomes	Grouping Variable	2 Months	4 Months	6 Months	13 Months
Child-rated Anxiety	Boys (M [SD])	28.39 (17.72)	26.59 (16.46)	24.49 (15.88)	22.14 (14.83)
	Girls (M [SD])	40.80 (18.41)	33.92 (17.64)	32.68 (18.62)	27.92 (13.96)
	Bootstrap Mean Difference (SE)	12.41 (2.76)**	7.33 (2.30)**	8.19 (2.20)**	5.78 (2.00)**
	Black (M [SD])	38.42 (20.28) ^a	31.81 (17.38)	32.04 (19.30)	27.44 (14.79)
	White (M [SD])	25.87 (12.37) ^a	25.72 (12.55)	23.57 (14.86)	20.08 (11.82)
	Hispanic (M [SD])	35.86 (18.53)	32.60 (19.74)	28.16 (16.92)	25.99 (15.47)
	Brown-Forsythe F Value (df)	3.43* (2, 72.16)	1.37 (2, 97.04)	2.12 (2, 100.23)	2.13 (2, 86.12)
	Did not see in ICU before death (M [SD])	42.3 (20.52)	37.0 (17.89)	36.6 (18.30)	28.9 (14.22)
	Saw in ICU before death (M [SD])	32.3 (17.55)	26.6 (15.93)	23.5 (15.42)	22.3 (14.30)
	Bootstrap Mean Difference (SE)	9.96 (2.96)**	10.43 (2.31)**	13.10 (2.52)**	6.56 (2.05)**
Child-rated Depression	Did not see in ICU after death (M [SD])	39.2 (19.92)	32.1 (18.17)	32.1 (20.20)	26.9 (15.03)
	Saw in ICU after death (M [SD])	31.3 (17.28)	29.6 (16.77)	25.5 (14.13)	23.5 (13.92)
	Bootstrap Mean Difference (SE)	7.90 (2.66)**	2.54 (2.03)	6.64 (2.33)**	3.36 (1.90)
	Did not attend funeral (M [SD])	37.5 (20.49)	33.2 (19.52)	35.9 (21.58)	28.8 (20.99)
	Attended funeral (M [SD])	35.5 (18.90)	30.7 (17.17)	27.7 (16.71)	24.9 (13.07)
	Bootstrap Mean Difference (SE)	2.00 (3.32)	2.50 (3.87)	8.21 (3.80)*	3.87 (4.35)
	Did not see in ICU before death (M [SD])	9.4 (5.89)	8.3 (5.80)	7.5 (5.30)	5.2 (5.12)
	Saw in ICU before death (M [SD])	8.2 (5.68)	6.6 (4.84)	5.2 (4.32)	4.8 (4.11)
	Bootstrap Mean Difference (SE)	1.21 (0.77)	1.77 (0.64)**	2.23 (0.57)**	0.38 (0.69)
	Did not see in ICU after death (M [SD])	8.5 (5.41)	7.5 (5.43)	6.9 (5.43)	4.7 (4.97)
Child-rated Difficulty Focusing on Schoolwork	Saw in ICU after death (M [SD])	8.7 (6.16)	7.0 (5.19)	5.4 (4.04)	5.3 (4.10)
	Bootstrap Mean Difference (SE)	0.17 (0.67)	0.56 (0.56)	1.44 (0.52)**	0.67 (0.57)
	Did not attend funeral (M [SD])	8.9 (5.89)	9.2 (5.85)	8.4 (6.06)	4.8 (5.15)
	Attended funeral (M [SD])	8.6 (5.79)	7.0 (5.17)	5.8 (4.49)	5.1 (4.50)
	Bootstrap Mean Difference (SE)	0.30 (0.86)	2.21 (1.05)*	2.62 (0.91)**	0.26 (0.90)
	Boys (M [SD])	5.23 (3.13)	3.79 (2.92)	3.12 (2.74)	3.61 (3.03)
	Girls (M [SD])	4.14 (2.63)	4.22 (2.74)	3.66 (2.56)	3.70 (2.79)

Outcomes	Grouping Variable	2 Months	4 Months	6 Months	13 Months
	Bootstrap Mean Difference (SE)				
	Did not see in ICU before death (M [SD])	1.09 (0.44) *	0.43 (.34)	0.53 (0.38)	0.08 (0.40)
	Saw in ICU before death (M [SD])	4.07 (2.73)	4.08 (2.73)	3.98 (2.87)	3.17 (2.91)
	Bootstrap Mean Difference (SE)				
	Did not see in ICU after death (M [SD])	0.80 (0.44)	0.07 (0.36)	0.95 (0.32) **	4.09 (2.81)
	Saw in ICU after death (M [SD])	4.27 (2.72)	3.92 (2.64)	3.86 (2.69)	0.92 (0.35) **
	Bootstrap Mean Difference (SE)				
		5.00 (3.06)	4.18 (3.00)	2.94 (2.51)	3.33 (2.85)
		0.73 (0.41)	0.26 (0.37)	0.92 (0.34) **	4.07 (2.90)
					0.74 (0.38)

*
p < .05

**
p < .01

Table 3.

Significant mothers' 2-13 month ratings of CBCL subscales by demographic variables.

		2 months (T1) M (SD)	4 months (T2) M (SD)	6 months (T3) M (SD)	13 months (T4) M (SD)
Age group	School-age (n=73)	3.33(3.41)	2.70 (3.14)	2.74 (3.57)	2.10 (2.94)
	Teens (n=32)	3.06 (2.29)	2.32 (2.51)	1.76 (2.36)	1.35 (1.41)
	Bootstrap Mean diff (SE)	0.27 (0.45)	0.39 (0.35)	0.98 (0.44) *	0.75 (0.26) **
Gender	Male (n=45)	2.59 (3.06)	1.96 (2.61)	1.97 (3.02)	1.29 (2.22)
	Female (n=60)	3.74 (3.10)	3.05 (3.13)	2.87 (3.48)	2.38 (2.83)
	Bootstrap Mean diff (SE)	1.15 (0.30) **	1.09 (0.28) **	0.90 (0.34) **	1.09 (0.27) **
Saw in ICU/ED after death?	No (n=54)	2.90 (2.79)	2.43 (2.82)	2.54 (3.45)	1.95 (3.04)
	Yes (n=51)	3.69 (3.47)	2.75 (3.11)	2.38 (3.13)	1.83 (1.95)
	Bootstrap Mean diff (SE)	0.79 (0.25) **	0.32 (0.21)	0.16 (0.28)	0.12 (0.20)
Attend funeral?	No (n=18)	3.50 (2.11)	3.44 (3.72)	3.17 (3.59)	0.81 (1.38)
	Yes (n=87)	3.20 (3.28)	2.37 (2.74)	2.28 (3.23)	2.05 (2.72)
	Bootstrap Mean diff (SE)	0.30 (0.30)	1.07 (0.39) **	0.88 (0.39) *	1.24 (0.18) **
Withdrawn					
Age group	School-age (n=73)	1.72 (2.19)	1.40 (2.02)	1.26 (1.85)	1.03 (1.66)
	Teens (n=32)	2.96 (3.08)	2.46 (2.38)	2.38 (1.85)	2.04 (2.11)
	Bootstrap Mean diff (SE)	1.25 (0.36) **	1.06 (0.30) **	1.12 (0.28) **	1.01 (0.25) **
Saw in ICU/ED before death?	No (n=44)	1.54 (2.33)	1.74 (2.23)	1.38 (1.53)	0.94 (1.03)
	Yes (n=61)	2.35 (2.60)	1.70 (2.16)	1.71 (2.41)	1.67 (2.34)
	Bootstrap Mean diff (SE)	0.81 (0.26) **	0.04 (0.20)	0.33 (0.17) *	0.73 (0.14) **
Saw in ICU/ED after death?	No (n=54)	1.82 (2.45)	1.46 (2.05)	1.44 (1.75)	1.09 (1.65)
	Yes (n=51)	2.38 (2.61)	2.00 (2.30)	1.72 (2.42)	1.60 (2.06)
	Bootstrap Mean diff (SE)	0.57 (0.20) **	0.55 (0.17) **	0.28 (0.18)	0.51 (0.14) **
Attend funeral?	No (n=18)	2.00 (2.26)	2.69 (2.70)	1.44 (1.79)	0.63 (1.09)
	Yes (n=87)	2.09 (2.59)	1.51 (2.02)	1.61 (2.13)	1.46 (1.94)
	Bootstrap Mean diff (SE)	0.09 (0.21)	1.18 (0.27) **	0.17 (0.24)	0.84 (0.10) **

		2 months (T1) M (SD)	4 months (T2) M (SD)	6 months (T3) M (SD)	13 months (T4) M (SD)
Somatic Complaints					
Age group	School-age (n=73)	1.71 (2.39)	1.15 (1.61)	1.17 (1.78)	0.88 (1.66)
	Teens (n=32)	1.88 (2.52)	2.06 (2.62)	1.01 (1.81)	0.93 (1.16)
	Bootstrap Mean diff (SE)	0.17 (0.35)	0.91 (0.25)**	0.15 (0.27)	0.04 (0.21)
Gender	Male (n=45)	1.25 (2.05)	1.40 (2.04)	1.25 (2.03)	0.62 (1.40)
	Female (n=60)	2.15 (2.61)	1.45 (2.00)	1.03 (1.56)	1.12 (1.61)
	Bootstrap Mean diff (SE)	0.90 (0.23)**	0.05 (0.25)	0.22 (0.22)	0.50 (0.17)**
Race/ethnicity	White (n=17)	1.73 (2.41)	1.82 (1.94)	2.11 (2.18) ^a	1.76 (1.99)
	Black (n=50)	1.71 (2.34)	1.60 (1.90)	1.11 (1.76)	0.66 (1.13)
	Hispanic (n=38)	1.88 (2.64)	1.03 (2.15)	0.57 (1.29) ^a	0.77 (1.67)
	Brown-Forsythe F (df)	0.04 (2, 41.18)	1.27 (2, 68.59)	4.60 (2, 50.02)*	2.76 (2, 42.41)
Saw in ICU/ED before death?	No (n=44)	1.48 (2.03)	1.43 (1.83)	1.33 (2.00)	0.62 (1.07)
	Yes (n=61)	1.89 (2.58)	1.43 (2.14)	0.97 (1.59)	1.17 (1.85)
	Bootstrap Mean diff (SE)	0.41 (0.31)	0.001 (0.24)	0.35 (0.20)	0.55 (0.09)**
Saw in ICU/ED after death?	No (n=54)	1.73 (2.35)	1.51 (2.17)	1.30 (2.03)	0.69 (1.27)
	Yes (n=51)	1.79 (2.52)	1.33 (1.83)	0.91 (1.42)	1.18 (1.81)
	Bootstrap Mean diff (SE)	0.06 (0.22)	0.18 (0.19)	0.36 (0.16)	0.49 (0.09)**
Attend funeral?	No (n=18)	2.25 (2.73)	1.00 (1.46)	0.44 (0.98)	0.38 (0.81)
	Yes (n=87)	1.68 (2.38)	1.46 (2.07)	1.28 (1.89)	1.01 (1.63)
	Bootstrap Mean diff (SE)	0.57 (0.25)*	0.46 (0.32)	0.84 (0.11)**	0.64 (0.08)**
Rule Breaking Behaviors					
Saw in ICU/ED after death?	No (n=54)	1.88 (2.69)	0.95 (1.40)	1.35 (2.23)	1.24 (1.96)
	Yes (n=51)	1.85 (2.17)	1.83 (2.22)	1.66 (2.16)	1.60 (1.82)
	Bootstrap Mean diff (SE)	0.03 (0.23)	0.88 (0.19)**	0.31 (0.22)	0.36 (0.24)

* p<.05

** p<.01

Table 4.

Significant fathers' 2-13 month ratings of CBCL subscales by demographic variables.

		2 months (T1) M (SD)	4 months (T2) M (SD)	6 months (T3) M (SD)	13 months (T4) M (SD)
Gender	Male (n=18)	0.89 (1.68)	0.42 (0.74)	0.71 (1.49)	0.50 (0.94)
	Female (n=19)	3.06 (4.77)	1.92 (2.90)	1.56 (1.99)	1.89 (2.85)
	Bootstrap Mean diff (SE)	2.17 (0.87) **	1.50 (0.36) **	0.85 (0.37) **	1.39 (0.54) *
Saw in ICU/ED before death?	No (n=14)	2.70 (5.27)	1.30 (2.42)	1.93 (2.37)	2.08 (3.15)
	Yes (n=23)	1.69 (2.96)	1.14 (2.21)	0.71 (1.19)	0.74 (1.33)
	Bootstrap Mean diff (SE)	1.01 (1.22)	0.16 (0.45)	1.22 (0.40) *	1.34 (0.60)
Saw in ICU/ED after death?	No (n=15)	0.67 (0.90)	0.68 (1.18)	0.40 (0.63)	0.92 (1.31)
	Yes (n=22)	2.90 (4.59)	1.53 (2.72)	1.69 (2.15)	1.50 (2.74)
	Bootstrap Mean diff (SE)	2.24 (0.38) **	0.85 (0.27) **	1.29 (0.28) **	0.58 (0.34)
Withdrawn					
Age group	School-age (n=26)	1.29 (2.40)	0.94 (1.74)	0.89 (1.58)	0.65 (1.34)
	Teens (n=11)	2.57 (3.72)	1.90 (2.51)	1.80 (2.44)	1.11 (1.36)
	Bootstrap Mean diff (SE)	1.29 (0.45) **	0.96 (0.35) **	0.91 (0.43)	0.46 (0.33)
Saw in ICU/ED before death?	No (n=14)	0.80 (1.75)	0.80 (1.31)	1.07 (1.54)	0.92 (1.71)
	Yes (n=23)	2.16 (3.31)	1.43 (2.27)	1.17 (2.06)	0.68 (1.06)
	Bootstrap Mean diff (SE)	1.37 (0.36) **	0.64 (0.27) *	0.10 (0.26)	0.24 (0.24)
Saw in ICU/ED after death?	No (n=15)	0.75 (1.36)	0.54 (0.90)	0.27 (0.46)	0.17 (0.39)
	Yes (n=22)	2.52 (3.61)	1.67 (2.39)	1.73 (2.21)	1.15 (1.57)
	Bootstrap Mean diff (SE)	1.77 (0.14) **	1.12 (0.15) **	1.46 (0.11) **	0.98 (0.14) **
Attend funeral?	No (n=5)	2.00 (2.45)	1.25 (1.89)	1.40 (2.19)	2.50 (2.12)
	Yes (n=32)	1.76 (3.09)	1.21 (2.04)	1.09 (1.84)	0.67 (1.24)
	Bootstrap Mean diff (SE)	0.24 (0.36)	0.04 (0.54)	0.31 (0.43)	1.83 (1.08) **
Somatic Complaints					
Age group	School-age (n=26)	1.18 (2.22)	0.48 (1.26)	0.48 (1.09)	0.13 (0.46)
	Teens (n=11)	2.07 (2.95)	1.50 (1.84)	0.60 (1.08)	0.33 (0.50)

		2 months (T1) M (SD)	4 months (T2) M (SD)	6 months (T3) M (SD)	13 months (T4) M (SD)
Gender	Bootstrap Mean diff (SE)	0.89 (0.68)	1.02 (0.32) **	0.12 (0.20)	0.20 (0.09) *
	Male (n=18)	1.00 (1.97)	0.65 (1.32)	0.24 (0.75)	0.07 (0.27)
	Female (n=19)	2.06 (2.94)	0.89 (1.68)	0.75 (1.25)	0.28 (0.57)
	Bootstrap Mean diff (SE)	1.06 (0.69)	0.24 (0.27)	0.52 (0.20) **	0.21 (0.06) **
Saw in ICU/ED before death?	No (n=14)	1.90 (3.32)	0.33 (0.89)	0.64 (1.15)	0.23 (0.60)
	Yes (n=23)	1.38 (2.21)	1.00 (1.71)	0.43 (1.04)	0.16 (0.37)
	Bootstrap Mean diff (SE)	0.52 (0.87)	0.67 (0.21) **	0.21 (0.16)	0.07 (0.04)
	No (n=5)	3.75 (4.35)	0.75 (1.50)	1.00 (1.41)	0.50 (0.71)
Attend funeral?	Yes (n=32)	1.25 (2.16)	0.77 (1.52)	0.44 (1.01)	0.17 (0.46)
	Bootstrap Mean diff (SE)	2.50 (0.28) **	0.02 (0.54)	0.56 (0.14) **	0.33 (0.35)
Rule Breaking Behaviors					
Age group	School-age (n=26)	2.05 (3.08)	1.08 (2.02)	0.85 (1.17)	0.96 (1.87)
	Teens (n=11)	1.64 (2.74)	1.13 (1.84)	1.33 (2.59)	.001 (.001)
	Bootstrap Mean diff (SE)	0.40 (0.60)	0.04 (0.55)	0.48 (0.58)	0.96 (0.24) **
	No (n=15)	1.87 (2.92)	0.77 (1.74)	0.73 (0.88)	0.58 (1.00)
Saw in ICU/ED after death?	Yes (n=22)	1.90 (2.99)	1.30 (2.07)	1.15 (2.01)	0.75 (1.94)
	Bootstrap Mean diff (SE)	0.04 (0.44)	0.53 (0.38)	0.42 (0.13) **	0.17 (0.31)
	No (n=5)	4.00 (5.66)	3.00 (3.83)	2.80 (3.11)	4.00 (5.66)
	Yes (n=32)	1.63 (2.42)	0.84 (1.48)	0.70 (1.13)	0.47 (0.97)
Attend funeral?	Bootstrap Mean diff (SE)	2.38 (1.42)	2.16 (0.72) **	2.10 (0.29) **	3.53 (2.84)
Aggressive Behaviors					
Age group	School-age (n=26)	5.03 (5.90)	3.45 (5.38)	2.56 (3.42)	2.73 (3.51)
	Teens (n=11)	3.14 (3.30)	2.02 (3.76)	1.61 (2.72)	0.89 (2.32)
	Bootstrap Mean diff (SE)	1.89 (1.18)	1.42 (1.26)	0.94 (0.82)	1.84 (0.79) **
	No (n=14)	6.20 (5.27)	4.82 (6.15)	3.14 (3.82)	3.39 (3.92)
Saw in ICU/ED before death?	Yes (n=23)	3.57 (4.91)	2.17 (4.14)	1.79 (2.80)	1.40 (2.59)
	Bootstrap Mean diff (SE)	2.63 (0.92) **	2.65 (1.05) **	1.36 (0.65) *	1.99 (0.68) **

		2 months (T1) M (SD)	4 months (T2) M (SD)	6 months (T3) M (SD)	13 months (T4) M (SD)
Saw in ICU/ED after death?	No (n=15)	3.33 (4.55)	3.15 (5.48)	1.80 (2.91)	2.43 (3.50)
	Yes (n=22)	4.99 (5.43)	2.95 (4.73)	2.64 (3.47)	2.08 (3.25)
	Bootstrap Mean diff (SE)	1.65 (0.47)**	0.20 (0.25)	0.84 (0.13)**	0.35 (0.27)
Attend funeral?	No (n=5)	8.68 (11.29)	7.25 (8.62)	4.00 (5.05)	8.79 (2.54)
	Yes (n=32)	3.75 (3.74)	2.47 (4.16)	3.03 (2.89)	1.77 (2.86)
	Bootstrap Mean diff (SE)	4.93 (2.22)	4.79 (0.91)**	1.97 (0.16)**	7.02 (1.29)**

*
p<.05**
p<.01