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Surviving Siblings' Illnesses, Treatments/Health Services over 13 Months after a Sibling's Death

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Abstract

Two million children experience sibling death annually and have problems that require clinical intervention although few receive such help. Effects on surviving siblings' mental health has been well documented, however their physical health has not. This study described surviving siblings' illnesses, treatments/health services at 2, 4, 6, and 13 months post-sibling death. The 132 children (76 girls, 56 boys, M10.6 years, SD 3.43); 30% Hispanic, 51% Black, 26% White were recruited via hospital ICUs and published obituaries. Using a longitudinal design, parents reported types and numbers of surviving siblings' illnesses, treatments/health services, and dates post-sibling death. Most of the 207 illnesses and 674 treatments/health services occurred in the first 6 months postsibling death. While girls had more illnesses (131) than boys (76) and Hispanic children had more illnesses than White or Black children, these differences were not statistically significant. Girls accounted for 66% of the treatments/health services and boys 34%. There was no significant difference in treatments/health service use by gender of the children (F = 1.00, p = .32). Hispanic children had significantly more treatments/health service use than Black children (F = 6.81, p = .002). Sibling death affects surviving siblings' physical health. Study data document the importance of monitoring the health, treatments and health service use of surviving siblings especially in the first 6 months after a sibling death, regardless of the child's gender. On average, Hispanic children had greater health service use, which may warrant greater attention.

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Author Contributions D.A.B. and J.M.Y. designed and wrote the study, analyzed the data and drafted the results. R.M.R., C.L.C., and T. F.P. collaborated in the design of the study and in the writing and editing of the final manuscript.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in this study involving human participants were in accord with the ethical standards of the Florida International University and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual parent participants and assent from all participating surviving siblings included in the study.

Keywords

Children's illnesses; Sibling death; Sibling bereavement; Child death; Children's treatments/health services

Introduction

Almost 2 million children each year experience the loss of a sibling with devastated parents and a changed family. Five hundred thousand of these sibling survivors have problems that require clinical intervention although few receive such help (Packman et al. 2006). Children's grief, depression, post-traumatic stress disorder (PTSD) and psychiatric hospitalization (Barrera et al. 2002; Birenbaum 2000; Charles and Charles 2006) and psychosocial outcomes (Rosenberg et al. 2015) are well documented after sibling death. Effects on surviving siblings' physical health, however, are less well known. Morbidity data over the first year after a sibling's death have not been reported but are essential for developing timing, type and duration of interventions to maintain or improve surviving children's health after sibling death.

Fifty percent or more of children who have lost a sibling have behavior problems (McCown and Davies 1995). These surviving children respond with anger, aggression, guilt, nightmares, depression, separation anxiety, fear of being alone, seeking parental affection, hopelessness, trouble concentrating, poor school performance, and suicidal thoughts and attempts. Research has demonstrated that close sibling relationships predispose surviving siblings to complicated bereavement reactions including higher depression and anxiety (Lövgren et al. 2016), poorer mental health and quality of life, and increased risk of low self-esteem (Eilegård et al. 2013). Fletcher et al. (2013), studying consequences of sibling death on young adults, found that effects were greatest for surviving sisters. They had fewer years of schooling and lower labor market earnings, especially if the death was from a sudden illness.

Bolton et al. (2016) examined mental disorders and treatment use among bereaved siblings and the general population in Canada. In the 2 years after the death, bereaved siblings had significantly higher rates of mental disorders than controls; depression rates from pre-death to post-death were significantly higher for surviving siblings under 13 years of age. For those over 13, 25% were diagnosed with a mental disorder (vs. 17% of controls), and they had higher rates of almost all mental disorder outcomes than controls, including twice the rate of suicide attempts. Stikkelbroek et al. (2016), studying the mental health of adolescents before and after the death of a parent or sibling, found that internalizing problems, especially depression, were higher after loss of a sibling than after loss of a parent. This finding was not statistically significant, however.

Grief and bereavement responses to a sibling's death can be complicated and lifelong (Sveen et al. 2014). Heberman-Mash et al. (2013) studied 107 young adults (17–29) who lost a sibling within the past 3 years (M= 1.63 years) and found that those who lost a sibling were more likely to have complicated grief, higher levels of grief, depression and somatic symptoms than those who lost a close friend or had not experienced a loss. Following loss of

a sibling to sudden infant death syndrome (SIDS), sibling survivors demonstrated significantly elevated behavioral problems almost 3 years later (Hutton and Bradley 1994). Deaths that are sudden, violent, and/or stigmatized are associated with increased mortality and more prolonged grief, bereavement, psychological problems, and health impairments (Rostila et al. 2012, 2014). Lohan and Murphy (2001) reported that surviving adolescents continue to have multiple grief reactions and behavioral changes up to 2 years after a sibling's sudden or violent death. Samples in these studies were White or race and ethnicity was not reported.

Research on children's physical health after sibling death is limited. Most studies of bereaved siblings' morbidity and mortality have been conducted on adolescents and adults who lost a sibling using national data sets from Sweden and Denmark. Virk et al. (2016), using the Danish Civil Registry System, found evidence of an increase in the rate of type 1 diabetes among the more than 94,000 children exposed to be reavement through loss of a sibling (5 years or greater). Lu et al. (2016) studied the risk of human papilloma virus (HPV) infection and cervical cancer in over 2 million women in Sweden and found bereavement was associated with a 62% increased risk of HPV16 infection, high viral load and recurrent infection. They suggested that this association may be attributed to stress-induced oncogenic HPV infections. Rostila et al. (2012), using Swedish registries, studied mortality after sibling death in adults (18-69 years) and found that mortality risk was stronger in younger adults (18–29 years) and over longer term follow-up (>1 year) than in the first year after the death. Studies of adults who lost a sibling up to 18 years since the bereavement had associated increases in mortality from myocardial infarction and fatal stroke (Rostila et al. 2013a, b). In one study of 60 White men and women, including siblings, Mitchell et al. (2009) found that a close relationship to a deceased sibling demonstrated no differences in physical health after controlling for age and gender effects. Surviving sibling's morbidity data over the first year after a sibling's death have not been reported.

Most studies on children's response to sibling death are from sibling cancer deaths (Nolbris et al. 2014). Existing studies also suffer from a number of methodological weaknesses. Many studies did not collect data from the surviving siblings directly, but rather collected data on parent's perceptions of the surviving children's responses. However, research indicates that children's responses to death of a sibling and parent's perceptions of their children's responses differ (Lohan and Murphy 2001; Roche et al. 2016). Most studies have small samples ranging from single case studies to samples of 20–30 (Christian 2007; Tonkins and Lambert 1996). Many samples are recruited from support groups, introducing sample bias. Almost all samples include only White middle- or upper-income families and little to no minority representation (Hogan and DeSantis 1994; McCown and Davies 1995; McHale et al. 2007). Studies include deaths of newborn to adult siblings in the same sample and data collection has occurred well after the sibling's death, introducing significant recall bias (Rosen 1985). The purpose of this study was to describe the pattern of surviving sibling's illnesses, treatments and health service use over the first 13 months after sibling death.

Method

Participants

Children (6–18 years old) whose sibling (neonate through 18 years) died at least 1 h after admission to the NICU, PICU, or ED and their parents (White non-Hispanic, Black non-Hispanic, Hispanic/Latino) were recruited from 4 South Florida children's hospitals and published obituaries. All parents were at least 18 years of age and understood spoken English or Spanish.

Sibling inclusion criteria: (1) lived with deceased sibling before PICU/ED admission or with the mother of the deceased neonate before NICU admission, (2) lived with the same parent(s) since the death and (3) in their age-appropriate grade in school \pm 1 year. Exclusion criteria: (1) conditions that render a child unable to participate verbally—e.g., cerebral palsy, severe brain damage, severe autism—but the family's other children remained eligible, (2) living in foster care before or after the death, and death of a parent or more than one sibling in the same event because the child will be dealing with the death of more than one nuclear family member at the same time. In two-parent families both parents were asked to participate in the study. In single-parent families, non-custodial parents were invited to participate if the custodial parent provided his/her name and contact information.

The sample consisted of 132 surviving siblings (76 girls, 56 boys), 70 mothers and 26 fathers in 71 families (Table 1). The deceased siblings died in a PICU (63%), NICU (24%), or ED (13%) in one of 18 health care facilities throughout Florida. Deceased siblings, categorized by age, included: 37% teens, 37% infants, 21% school aged, and 5% preschoolers. Most died as a result of failed CPR and limiting treatment. Forty eight percent of the surviving siblings had Medicaid insurance, 30% did not provide these data, and the remainder had a variety of other types of private insurance.

Procedure

The study was approved by the University's Institutional Review Board (IRB) and the IRBs of 4 South Florida hospitals. Using a longitudinal, repeated measures design, data on children's illnesses, treatments and health service use were collected at 2, 4, 6, and 13 months post-sibling death. Data obtained from the deceased infant's/child's hospital record included dates of birth and death, admitting diagnoses and condition, and mode (limiting treatment, withdrawing life support, unsuccessful resuscitation, brain death) and place of death (NICU/PICU/Emergency Department [ED]).

Clinical co-investigators at the hospitals identified Hispanic/Latino, White non-Hispanic, and Black non-Hispanic parents whose infant/child died in their NICU/PICU/ED and met study criteria and provided parents' names and contact information to the project. Research assistants (RAs) searched online obituary notices to identify families and then online databases for their contact information. Clinical coinvestigators provided addresses and phone numbers for any missed families from their facility. At 6–7 weeks after the death, we sent a letter (in Spanish and English) to families identified through the hospitals and the obituaries that described the study (Spanish and English), identified the bilingual RAs on the project, and provided the project phone number and email address. About 1 week after the

letter was sent, an RA called the family, further described the study, answered parents' questions, screened for inclusion/exclusion criteria, ascertained whether the family was willing to be in the study, and made an appointment to go to the family's home. At the home, the RAs again explained the study to the parent(s), answered any questions and obtained their signed consent for their participation, review of their deceased child's hospital record, and for the RA to talk with their eligible children about the study. The RA explained the study to the eligible children, answered their questions, and obtained their signature on an assent form. Children were not asked to participate if the parent did not give consent for the children to participate. Children who were 18 signed consent forms for their own participation. Those who became 18 during the study signed consent forms at that time. Only children who signed the assent form after their parent(s) gave consent were interviewed.

Child data were collected in English and parent data in the parent's preferred language (Spanish/English) by RAs fluent in both languages at 2, 4, 6, and 13 months post sibling NICU/PICU/ED death. Of the 281 families contacted and eligible, 71 (25%) participated. This participation rate is consistent with a systematic review of recruitment strategies in research with children with life-threatening illnesses (Hudson et al. 2017).

Measures

At 2 months after the sibling death, in the language of their choice (English or Spanish), parents completed a family demographic form which included data on: (a) the family—number of parents and children in the home, annual family income; (b) the parent(s)—age, race/ethnicity, education, marital status; (c) each surviving sibling—age, gender, race/ethnicity, grade in school; and (d) the deceased child—date of birth and death, gender, and cause of death. Data that could change (number of parents and children in the home, annual family income, and parent education and marital status) were updated at 13 months.

Data from the deceased sibling's hospital chart included: date and time of hospital and NICU/PICU/ED admission, date and time of death, date (and time for neonates) of birth, admitting diagnosis. Mode of death was categorized as: (a) "failed CPR," (b) "brain death," (c) "treatment limited," and (d) "life support withdrawn."

At 2, 4, 6, and 13 months parents reported on types and numbers of children's illnesses, treatments, and health service use since the death and dates for each as an indication of the surviving siblings' health. Data were collected on a standard form indicating the date and type of illness, treatment and health services used, reason for the service and charges (bill) for the service. Charges for routine health care and for non-routine physician visits, emergency room visits, urgent care visits, hospitalizations, follow up visits for the former, and mental health services for surviving siblings were collected from parents using bills for these services sent to them or copied to them from their insurance companies.

Data Analyses

Most analyses in this study were done with descriptive statistics (frequencies, means, and standard deviations). Differences in mean number of illnesses and treatments/health service use by gender were tested with two-sample t-tests and by race/ethnicity, with oneway

ANOVAs with Scheffe tests for post hoc comparisons. The interaction of gender and race/ethnicity was tested with 2-way ANOVA. Alpha level for statistical significance was set at . 05.

Results

Surviving Sibling's Illnesses

A total of 207 illnesses were reported by parents during the 13 months since the sibling's death with 64 (50%) of surviving siblings having at least one illness (Table 2). While girls had more illnesses than boys, this difference was not significant. By race/ethnicity, Hispanic children had more illnesses on average than White or Black children, but this difference was not statistically significant.

Most illnesses (64%) occurred in the first 6 months after the sibling's death. By 6 months 94% of gastrointestinal problems; 92% of allergies; 86% of the gynecological problems; 80% of the headaches; and 63% of the infections, eye problems and anxiety had occurred. The most frequent infections were upper respiratory infections which made up 39% of all infections, followed by ear infections at 13%.

Surviving Sibling's Treatments/Health Service Use

A total of 674 treatments/health services were used by 92 children (70%) during the 13 months after their sibling's death (Table 3). Most treatment/health service use (65%) occurred in the first 6 months after the death. By 6 months, 93% of psychiatric referrals, 78% of medication, 70% of pediatric visits, 67% of psychiatry therapy, 83% of dental visits, and 53% of specialist visits occurred. There was a period of relative quiescence in months 7 through 10 followed by an increase again in treatments/health service use in months 11 through 13. The amount of missing charge data precluded costing of treatment/health service use.

Surviving Sibling's Treatments/Health Service use by Gender and Racial Group

Of the 674 treatments/health service use, 442 (66%) were for girls and 232 (34%) for boys during the 13 months after their sibling's death (Table 4). There was no significant difference in treatments/health service use by gender of the children. Hispanic children had significantly more treatments/health service use than Black children. Hispanic children had 345 treatments/health service use compared to 122 for White children and 207 for Black children. The interaction of gender and race/ethnicity (two-way ANOVA) was not significant for illnesses or treatments/health service use.

Discussion

Most research on health effects after sibling loss has examined surviving sibling's mental health and mortality. The few studies examining surviving sibling's physical health were conducted years after the sibling death occurred using national datasets, mainly from Scandinavia. These studies have been retrospective, with largely White samples and sibling age at death varying from shortly after birth to years into adulthood, often in the same

sample. They provide little guidance for timing and specific types of interventions needed to prevent morbidity and promote health in surviving siblings in the difficult first year after a sibling's death. These data also are needed in supporting surviving siblings as a standard of care in pediatric oncology (Gerhardt et al. 2015).

This study's data provide a monthly pattern of surviving siblings' morbidity over the first 13 months after sibling NICU/PICU/ER death in a diverse sample of 132 children. Study data document the importance of monitoring the health, treatments and health service use of surviving siblings especially in the first 6 months after a sibling death, regardless of the child's gender. On average, Hispanic children had greater health service use, which may warrant greater attention. The 131 pediatric visits were for gastrointestinal and gynecological problems, allergies, headaches, infections and anxiety.

The pattern of illnesses and health service use at 6 months after the death and an increase in months 11–13 may be a reflection of events and important milestones after a child's death. In some cultures and/or religions events are held to commemorate the 6-month milestone of the death (Lobar et al. 2006). The 1-year anniversary of the death is a very sensitive period for families, often marked with events such as holding a mass for the deceased sibling, visiting the gravesite, balloon or butterfly releases, and family gatherings with celebration of life activities. The pattern of illnesses and health service use in surviving siblings also may reflect the parents' stress level at these milestones.

The increase in doctor visits in the first month after the sibling death and over the first 6 months may be a reflection of parents' hypervigilance of their other children. This is consistent with some parents wanting their remaining children to sleep with them in the days or weeks after their child's death (Brooten and Youngblut 2016). In the first month after the sibling's death, many parents needed physician reassurance that their surviving children were healthy.

The pattern of surviving sibling's physical health in this study is similar to that of parents in another study (Youngblut et al. 2013) during the first 13 months after their child's NICU/PICU death. Parents' (176 mothers, 73 fathers) morbidity showed acute illnesses, hospitalizations, and medication changes in month 1 continuing through month 6, relative quiescence in months 7–10, and an increase in months 11–13. Mothers reported 300 acute illnesses (primarily colds/flu, headaches, anxiety/depression, infections), and 89 hospitalizations. Fathers' morbidity followed a similar pattern but with less frequency: 104 acute illnesses and 9 hospitalizations (Brooten et al. 2018).

Although missing data on healthcare charges precluded the calculation of elevated healthcare costs following the death of a sibling, the increased use of pediatric visits, psychiatric therapy, and medications in the 6 months following the death of a sibling suggest a significant healthcare cost burden. The costs of these healthcare services are likely to be shared between parents and insurance companies. With almost half of the children covered by Medicaid, a large share of the healthcare cost burden is borne by taxpayers. Use of healthcare services was the highest (65%) in the first 6 months following the death of a sibling. This finding suggests that the optimal time for intervention is immediately following

the sibling's death. Utilization rates among Hispanic children were substantially higher than for White children, while utilization rates for Black children were substantially lower than for White children. Future research should explore the reasons for these differences according to race/ethnicity.

There is very little literature on financial costs of treatments for surviving siblings following the loss of a sibling that include unscheduled physician visits, emergency room visits, hospitalizations, and medications. The literature that is available is on surviving sibling's experiences with support and treatment groups, summer camps, and school intervention programs. However, the total charges for these interventions are not reported. The present study findings demonstrate the need for early identification and intervention to prevent human costs on the family and the surviving siblings as well as increased financial costs to the family and society.

Limitations and Future Research

In this heavily minority sample, most parents were high school graduates or had some college education, and 75% had an annual income less than \$50,000. Fewer fathers participated than mothers, a finding common to such research. Data on surviving sibling morbidity were from parent report with the limitations of parent report. It is not clear if findings would hold with a greater White and more affluent sample.

Additional studies of Hispanic and Black non-Hispanic children and adolescents, as well as those from other racial/ethnic groups, would help our understanding of racial/ethnic and age differences in surviving siblings' physical health following a sibling's death. Comparisons of surviving siblings' reports of their physical health and parents' reports of surviving siblings' physical health would allow identification of similarities and differences in these perspectives.

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Table 1

Characteristics of parents, surviving siblings, and deceased siblings

		(0/=) (1/00)	(
Age	[M(SD)]	35.9 (7.13)	39.0 (7.37)
Race/ethnicity	Hispanic $[n (\%)]$	23 (33%)	8 (30%)
	Black non-Hispanic $[n(\%)]$	30 (43%)	9 (35%)
	White non-Hispanic $[n(\%)]$	17 (24%)	9 (35%)
Education	<pre><high <math="" school="">[n(\%)]</high></pre>	19 (27%)	8 (31%)
	High school graduate-some college $[n(\%)]$	28 (40%)	13 (50%)
	College graduate [n (%)]	23 (33%)	5 (19%)
Partnered?	Yes $[n(\%)]$	54 (77%)	24 (92%)
	No [n(%)]	16 (23%)	2 (8%)
Family income $(N=71)$	<\$20,000 [n (%)]	28	28 (39%)
	\$20,000–\$49,999 [n (%)]	26	26 (37%)
	\$50,000 and greater $[n(\%)]$	17	17 (24%)
Surviving siblings' characteristics ($N=132$)			
Age	[M(SD)]	10.0	10.6 (3.43)
Gender	Male $[n (\%)]$	99	56 (42%)
	Female [n (%)]	9/	76 (58%)
Race/ethnicity	Hispanic $[n (\%)]$	39	39 (30%)
	Black non-Hispanic $[n(\%)]$	<i>L</i> 9	67 (51%)
	White non-Hispanic $[n(\%)]$	26	26 (19%)
Deceased siblings' characteristics ($N=71$)			
Age at death (months)	[M(SD)]	92.3	92.3 (82.28)
Gender	Male $[n (\%)]$	44	44 (62%)
	Female [n (%)]	27	27 (38%)
Where death occurred	Pediatric intensive care unit $[n (\%)]$	45	45 (63%)
	Neonatal intensive care unit $[n (\%)]$	17	17 (24%)
	Emergency department $[n(\%)]$	6	9 (13%)
Mode of death	Failed CPR $[n(\%)]$	25	25 (35%)
		-	

Parent Characteristics		Mothers (N=70) Fathers (N=26)
	Brain death $[n(\%)]$	11 (16%)
	Life support withdrawn $[n(\%)]$	10 (14%)
	Stillborn $[n(\%)]$	3 (4%)
	Don't know $[n(\%)]$	1 (1%)

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Table 2

Surviving siblings' illnesses 1-13 months after sibling death

Illnesses	1 mo	2 mo	2 mo 3 mo	4 mo	5 mo	6 mo	7 mo	8 mo	om 6	10 mo	11 mo	10 mo 11 mo 12 mo 13 mo	13 mo	Total
Infection	7	7	9	14	8	3	3	2	5	5	1	3	7	71
Depression	-	-	2	2	2	_	2	1	1	2	2	1	2	20
Anxiety	∞	-	ı	-	ı	ı	П	ı	-	4	ı	ı	0	16
Asthma	ı	3	ı	ı	_	_	ı	-	4	-	-	3	ı	15
Allergy	ı	ı	S	33	2	-	ı	ı	ı	ı	ı			13
Gastrointestinal	4	-	9	4	_	_	ı	ı	ı	ı	ı	ı	-	18
Headache	3	2	1	-	ı	-	-	ı	ı	ı	1	1	1	10
Eye problems	ı	-	1	ı	2	-	ı	ı	ı	1	1	-	ı	∞
Pain	ı	ı	ı	ı	ı	ı	ı	ı	ı	ı	3	ı	2	5
Gynecologic	-	-	I	-	2	-	1	I	ı	ı	ı	ı	ı	7
Orthopedic	ı	-	2	ı	-	-	ı	ı	ı	2	ı	ı	-	∞
Other	-	4	3	ı	2	2	ı	I	ı	ı	ı	2	2	16
Totals	25	22 *	26*	26*	21	13	8	4	11	15	6	11	16**	207

* Missing data for 4 children;

missing data for 10 children

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Table 3

Surviving siblings' treatments and health service use 1-13 months after sibling death

Treatments/health service use	1 mo	2 mo	3 то	4 mo	5 mo	om 9	7 mo	8 mo	om 6	10 mo	11 mo	12 mo	13 mo	Total
Pediatric visit	25	∞	16	18	18	7	4	,	9	3	∞	7	11	131
Referrals														
Psych	9	5	ı	2	ı	ı	1	ı	ı	_	1	ı	ı	14
Other	ı	2	33	1	1	1	1	1	1	1	1	1	1	S
Specialist Visits	2	3	10	10	10	∞	4	3	2	9	∞	S	10	81
Medications	7	12	10	12	10	9	2	ı	2	_	2	_	∞	73
Therapy														
Psych	20	21	25	25	21	18	10	10	9	9	12	15	4	193
Other	_	2	2	2	2	2	2	2	2	2	2	2	2	25
Laboratory	ı	4	2	4	1	2	2	2	3	2	5	4	2	32
ER/Urgent Care	-	2	∞	4	4	ı	2	3	2	4	4	3	ı	37
Dental	2	_	∞	7	7	1	ı	1	_	33	ı	ı	_	30
Annual school checkup and shots	-	1	4	2	33	3	2	1	1	1	5	1	7	27
Hospitalization	ı	ı	ı	ı	ı	ı	ı	_	_	ı	ı	ı	ı	2
Other, X-ray/scans, allergy, surgery	_	13	2	_	_	ı	ı	_	ı	_	_	2	_	24
Totals	99	73	06	87	9/	46	28	22	25	29	47	39	46	674

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Table 4

Comparison of surviving siblings' total illnesses, treatments/ health service use by child gender and race/ethnicity

	Total illnesses	Statistic	Total illnesses Statistic Total treatments & health service use Statistic	Statistic
Group	M (SD)		M (SD)	
All surviving siblings ($N = 128$) 1.6 (2.50)	1.6 (2.50)	NA	5.3 (8.44)	NA
Surviving sibling gender		t = 0.70		t = 1.00
Male $(n = 53)$	1.4 (2.64)		4.4 (6.55)	
Female $(n=75)$	1.8 (2.40)		5.9 (9.54)	
Surviving sibling race/ethnicity		F = 1.37		$F = 6.81^*$
Black non-Hispanic $(n = 64)$	1.4 (1.90)		3.2 (4.32) ^a	
Hispanic $(n=37)$	2.2 (3.30)		9.3 (12.08) ^a	
White non-Hispanic $(n=27)$	1.4 (2.45)		4.5 (8.15)	

p = 0.002

^aSignificantly different pair