

12-2015

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Recommended Citation

Brooten, Dorothy; Youngblut, JoAnne M.; Hannan, Jean; Caicedo, Carmen; Roche, Rosa M.; and Malkawi, Fatima, "Infant and Child Deaths: Parent Concerns about Subsequent Pregnancies" (2015). *Nicole Wertheim College of Nursing and Health Sciences*. 44.
https://digitalcommons.fiu.edu/cnhs_fac/44

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HHS Public Access

Author manuscript

J Am Assoc Nurse Pract. Author manuscript; available in PMC 2016 December 01.

Published in final edited form as:

J Am Assoc Nurse Pract. 2015 December ; 27(12): 690–697. doi:10.1002/2327-6924.12243.

Infant and Child Deaths: Parent Concerns about Subsequent Pregnancies

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Abstract

Purpose—examine parents' concerns about subsequent pregnancies after experiencing an infant or child death (newborn to 18 years).

Data Sources—39 semi-structured parent (White, Black, Hispanic) interviews 7 and 13 months post infant/child death conducted in English and/or Spanish, audio-recorded, transcribed and content analyzed. Mothers' mean age was 31.8 years, fathers' was 39 years; 11 parents were White, 16 Black, 12 Hispanic.

Conclusions—Themes common at 7 and 13 months: wanting more children; fear, anxiety, scared; praying to God/God's will; thinking about/keeping the infant's/child's memory and at 7 months importance of becoming pregnant for family members; and at 13 months happy about a new baby. Parents who lost a child in NICU commented more than those who lost a child in

PICU. Black and Hispanic parents commented more on praying to God and subsequent pregnancies being God's will than White parents.

Implications for Practice—Loss of an infant/child is a significant stressor on parents with documented negative physical and mental health outcomes. Assessing parents' subsequent pregnancy plans, recognizing the legitimacy of their fears about another pregnancy, discussing a plan should they encounter problems and carefully monitoring the health of all parents who lost an infant/child is an essential practitioner role.

Introduction

Death of an infant or child is devastating for parents who must attend to arrangements for the child's body, tell children and family members of the death, and begin to deal with the death themselves. Later parents think about possibility having another child. Their thoughts are accompanied by feelings of ambivalence, anxiety, depression and fear about another infant or child loss (Lamb, 2002; Robinson, 2013). Anxiety, depression, anticipatory grief (expecting another loss) and suspending maternal attachment during the next pregnancy may prepare parents for the possibility of losing a subsequent pregnancy and reduce the impact should that occur (Gold, Leon and Chames, 2010).

This phenomenological study using semi-structured interviews with parents from 3 racial/ethnic groups 7 and 13 months following an infant's or child's NICU/PICU death analyzed parents' concerns about subsequent pregnancies. This is important since much of the research on pregnancy after infant or child death focuses on pregnancy, perinatal or newborn death and overwhelmingly includes White, married, middle class women (DeBackere, Hill, & Kavanaugh, 2008) despite the changing US population mix.

Literature Review

Pregnancy Anxiety

Research on subsequent pregnancy after perinatal loss indicates that anxiety during pregnancy is higher in: women and men with a history of loss (Blackmore et al., 2011); mothers than in fathers (Armstrong, 2002; Armstrong, 2004; Nazaré, Fonseca, & Canavaro, 2012); women without any children (Tsartsara & Johnson, 2006); and women who had a perinatal loss later in gestation (Cote-Arsenault & Dombeck, 2001). While anxiety decreased as pregnancy advanced (Cote-Arsenault, Donato & Earl, 2006), a short time frame between the loss and a subsequent pregnancy increased the risk of post-traumatic stress disorder (PTSD) (Turton, Huges, Evans, & Fainman, 2001). In another study, type of loss (pre-, peri- or postnatal) did not effect PTSD severity (Christiansen, Elklit & Olf, 2013). Anxiety in a subsequent pregnancy was not correlated with the number of living children but was correlated with the pregnant woman seeing and calling the provider more often (Cote-Arsenault, 2003). Higher anxiety levels during pregnancy have been associated with pregnancy complications (Dole et al., 2003; Mulder et al., 2002) and higher levels of postpartum depression (Field et al., 2003; Heron et al., 2004).

O'Leary and Thorwick (2006) interviewed 10 fathers who experienced a loss within a year. Fathers felt they: were not able to share their fear and anxiety in order to protect the

mothers; needed to be recognized by others; experienced social pressure to act strong, and could not ask for support even though they needed it.

Depression and Grief

After a perinatal loss depressive symptoms are higher in women than men (Armstrong, 2002; Armstrong, 2004) may be greater in women who conceive less than 12 months after a loss (Hughes, Turton, & Evans, 1999) and may remain up to seven years after the loss (Schwerdtfeger, & Shreffler, 2009). In a subsequent pregnancy the number of previous miscarriages/stillbirths significantly predicted symptoms of depression and anxiety (Blackmore et al., 2011). The association remained constant over the prenatal (18 and 32 weeks gestation) and postnatal (8, 21 and 33 months) periods indicating an enduring impact of previous prenatal loss that remained following birth of a healthy child.

Barr and Cacciatore (2008) in a largely White well-educated sample reported sustained levels of grief in women who wanted to become pregnant after perinatal loss but were unsuccessful. While grief decreased in women who became pregnant or who had a subsequent child, manifestations of grief can appear late after the loss (Wood & Quenby, 2010). Gaudet (2010) examined feelings of perinatal grief, depressive symptoms and perinatal attachment in 96 pregnant women who had experienced previous perinatal loss. Findings suggested that early conception following grief, stage of the prior pregnancy before the loss, a late pregnancy loss and a high number of losses appear to be risk factors for grief symptoms, high anxiety and weak prenatal attachment, findings similar to those of others (Bennett, Litz, Maguen, & Ehrenreich, 2008; Figueredo, Costa, Pacheco, Conde & Teixeira, 2007).

Lang et al. (2011) interviewed 13 bereaved couples at 2, 6, and 13 months after a fetal or infant death. Results indicated that the couples experienced ambiguity and grief concerning the viability of the infant, the physical process of pregnancy loss, making arrangements for the remains, and sharing the news with family and friends. Cowchock et al. (2011) in their pilot study of 15 women found that women who suffered from grief and PTSD symptoms found religion helpful in coping during their stressful subsequent pregnancies.

Other Parent Responses

Mothers have described perinatal loss as a life changing event with feelings of vulnerability, worry and uncertainty about the outcome of subsequent pregnancies (Cote-Arsenault & Morrison-Beedy, 2001; Moore, Parrish & Black, 2011). Women describe seeking reassurance from health care providers, changing providers, being hyper-vigilant and wanting additional testing in subsequent pregnancies (Robson, Leader, Bennett, & Dear, 2010). Compassionate, sensitive health care providers and knowing the medical cause for a previous pregnancy loss can reduce the intensity of grieving (Brooten et al., 2013). Mothers describe dates and milestones in the pregnancy loss including the gestational age of the previous loss, first detection of fetal movement and times when the fetal heartbeat was heard. They fear getting through these in the subsequent pregnancy (Cote-Arsenault & Mahlangu, 1999). The research on pregnancy after infant or child death however, focuses on pregnancy, perinatal or newborn loss and overwhelmingly includes White, married, middle

class women. It is not clear if the responses reported to date hold for more racially/ethnically diverse samples of women and men.

Methods

Data reported here are from a longitudinal mixed methods study examining parents' health and functioning following the ICU death of an infant or child. The study received IRB approval from the University and each study site. Parents (White non-Hispanic, Black non-Hispanic, Hispanic/Latino) who had lost a child in the Neonatal Intensive Care Unit (NICU) or Pediatric Intensive Care Unit (PICU) were recruited from 4 hospitals in South Florida and from death records from the Florida Department of Health's Office of Vital Statistics.

Parents were able to understand spoken English or Spanish. Parents who could not read English or Spanish had the questions read to them. *Inclusion criteria* for parents of deceased newborns were: 1) singleton pregnancy; 2) neonate born alive and lived for more than 2 hours. Inclusion criteria for parents with deceased infants/children from the PICU were: 1) patient in the PICU for more than 2 hours; 2) deceased child was 18 years of age or younger. *Exclusion criteria* were: 1) multiple gestation pregnancy if deceased newborn, 2) child in foster home before hospitalization and/or whose injury was suspected to be due to child abuse to eliminate extreme family conditions, 3) death of a parent in the illness/injury event, such as motor vehicle crashes, because the surviving parent would be dealing with the death of a spouse and a child simultaneously.

Procedure

Families were identified by clinician co-investigators at each study site. A letter was sent to each family (in Spanish and English) describing the study. Research assistants (health professional graduate students) called the families, screened for inclusion and exclusion criteria, described the study in Spanish or English, answered parents' questions, obtained verbal consent and scheduled the first data collection visit where written consent was obtained.

Data from 39 parents consenting to participate in the qualitative phenomenological portion of the larger study were collected at 7 and again at 13 months post infant/child death using semi-structured interviews. Using a standardized protocol with core questions and probes, at the 7 month interviews parents were asked for their perspective on the events around the time of their child's death. At the 13 month interviews parents provided their perspective on their lives and those of their families in the 6 months since the previous (7 month) interview and perspectives on the future.

The 39 semi-structured 7 and 13 month post death parent interviews were conducted in English and/or Spanish by research assistants (RAs) in the parent's home. The interview schedule was developed based on the purpose of the study, the literature, our own clinical expertise and discussion with 2 national and international study consultants with expertise in qualitative methods, grief in parents of deceased children, and instrument development. Interview questions and format were further reviewed by each of our clinical site coordinators for face validity, understandability and level of language. Interviews were

scheduled at 7 and 13 months after the death so that parents had time to reflect on their experience to identify aspects that were truly important to them and to avoid the 6 month and 1 year anniversaries of the infant's/child's death.

The qualitative data were analyzed using content analysis. Interviews were 1.5 to 2 hours, audio-recorded and transcribed verbatim. Transcripts were compared to audio-recordings for transcription accuracy by English and Spanish-speaking graduate students in health disciplines. Corrected transcripts were entered into Atlas.ti for analysis. Initial categories were developed by the investigators and 6 graduate students with relevant clinical expertise using an inductive approach with 6 transcripts. Text categorized as “future pregnancies” or “subsequent pregnancies” was then analyzed for subthemes. Two English-speaking and 2 bilingual Spanish-speaking graduate students using the subthemes and their operational definitions then categorized the interviews comparing and discussing their categories for each transcript. Any category inconsistencies were reviewed and discussed by the 2-coder teams until they reached consensus.

Results

Sample

Mothers were about 7 years younger than fathers on average; 11 parents were White, 16 Black and 12 Hispanic. See Table 1. At the 7-month interview, 31 parents, (23 mothers, 8 fathers) commented on “subsequent pregnancies,” 20 in English and 11 in Spanish. At 13 months 27 parents (25 mothers, 2 fathers) made comments on “subsequent pregnancies”, 21 in English and 6 in Spanish. Of the 31 mothers who made comments, 9 (29%) experienced a subsequent pregnancy during the 13-month study period.

The 39 parents lost 33 infant/children: twenty (61%) infants less than one year; seven (21%) preschool children; two (6%) school age; and 4 (12%) adolescents. Eighteen (54.5%) were male. Nineteen (58%) died in the PICU and 14 (42%) died in the NICU. Most frequent causes of death were congenital anomalies (24%), neurologic disorders (15%), infections (15%), respiratory problems (12%), accidents (9%) and prematurity (9%).

Common themes at 7 months post infant/child death were: wanting more children; fear, anxiety, scared; praying to God/God's will; thinking about/keeping the memory of the infant/child; and importance of becoming pregnant for family members. See Table 2.

Wanting more children—Almost half (44%) of the 7 month comments were about wanting another child. “The biggest thing on my mind is having a child” and “I definitely want another kid.”

“I'm looking forward to having more children -- healthy children um, hopefully more than one, maybe two.”

Fear, anxiety, scared—Experiencing the death of their infant/child brought the possibility of something going wrong in a future pregnancy for both men and women.

“We're afraid well, what.....what if it happens againso we are scared, um, really scared.”

“I don't think my wife could handle it and I know I can't, if something like this happened again.”

“You don't leave the place where one experiences a very strong pain—and depression.”

“Now that I am pregnant again it came...like all the memories came back to me and I have been depressed ever since...and by being depressed I've been sick a lot.”

“Maybe after I pass that 27-week mark and....and I'm feeling safe and secure...”

“I've been crazy since I found out [about being pregnant] and, um, I feel like I have to get the doctors every week just to make sure everything is ok.”

Praying to God/God's Will—Prayer can be comforting and helpful in coping with loss. Here, praying was for the health of a future child or children:

“I pray and hope to God my next baby is coming home ---- God is good whenever you pray.”

“I am praying and praying and praying”

At 7 months, five of the six comments about praying were made by Black women.

Importance of becoming pregnant for family members—Parents perceived pressure from family members – their parents, siblings, or other children – to have another child. Parents whose infant died in the NICU made most of the comments.

“My mom has, believe or not, 12 children. I am the only one without a grand baby for her and she is always, you know, just waiting and just ... even everybody in my brothers, everybody have children, so everybody was just quote ‘waiting’ for us to have a baby.”

“My daughter want me to have, what, two sisters and a brother, so three more kids.”

“My son still asks me if he can ... if he can have another brother.”

Thinking about/keeping the memory of the infant/child—Some comments reflect mothers' reactions to others statements or advice to forget about the deceased or to have another baby to replace the dead infant/child:

“That was kinda hurtful; that people would just think I am gonna forget her right away”

“I need to know that I can have a healthy baby. It's not to replace our [deceased] son” Other comments describe the mothers' needs or plans to incorporate the deceased into their ‘future’ family:

“I love this baby but they are different feelings, different affection towards the first one [deceased]. I speak to him a little about his little brother because -- he is a little angel who is looking after us who is also going to be a little angel for the new baby who is coming.”

“Hopefully, one day she [deceased] will have siblings and they will know about their sister and what she went through.”

Common themes at 13 months post infant/child death were: fear, anxiety and scared; wanting another child; being happy about a new baby; Praying to God/God's will; and thinking about/keeping the memory of the infant/child. See Table 3.

Fear, anxiety and scared—Parents continued to discuss their fears about a pregnancy, not wanting another pregnancy, and fears after a subsequent birth. One mother said, “I’m not gonna lie. I’m kinda scared to, you know ... we were trying to get pregnant.” Another said, “the heartaches and the fear and the pain...I can't bring myself to that.”

Some reported acting or feeling differently, being more worried in this pregnancy, as one mother said, “When we got to the ... the milestone of when I gave birth with [deceased] with this pregnancy ... I flipped out and I had to go to the hospital to be checked.” Another said, “Every little thing that went on scared me even more...any little problem.”

One husband said, “We were trying to get pregnant, you know. For her I'll do it, for me umm just too scared.” Another said, “Was scared when I found out she was pregnant and pregnant with the same sex baby...I just wasn't ready to deal with it.”

There was fear even after a subsequent birth: “It was scary even when I had my son...I didn't want to lose him to the disease.” “I still feel so much anxiety...now I think the anxiety is about the baby right now.”

And others worried about the effects on their other children: “Wonder how this will affect my children when they grow up and get married...are they gonna be anxious the first time they have a baby?”

Wanting another child—Parents, primarily mothers, continued to talk about wanting to have another child: “Really want another child, um it's something that's definitely remains the same” and “I'd like to have another child; one more.”

“I will be a parent again...whether it be through adoption or physically having my own.”

Happy about a new baby—Some families had a new baby by 13 months after the infant/child death and some parents seemed ambivalent. “Yeah it's like two conflicting feelings... that you are happy but it's also related to like a negative experience.” Some parents had the new baby tested for genetic problems: “We had him tested to find out if he had the disease or if he was a carrier.”

Others were just happy: “Really happy and excited. Um, it doesn't replace – [deceased], but --- you know, she brings happiness to myself and my family.”

“My son, I'm ecstatic. You know, he's the coolest little kid, and every...he doesn't really respond to me yet you know. He does little things that make me happy - um he smiles,--you know things like that. It's cool and it's just gonna get better.”

Praying to God/God's will—Black and Hispanic mothers attributed their situation, whether for conceiving or not conceiving another child, to God. None of the White mothers talked about a role for God in their situation.

“Now, if God ah blesses us with another child, He will. If He decides that that's not, you know, for us, that is not for us. That's something that I ... I can accept.”

“He giveth and He taketh away and He giveth also you know --- so I feel blessed.”

Thinking about/keeping the memory of the infant/child—Parents continued to keep the memory of their deceased infant/child alive for themselves and others. One parent said, “Like somebody said at a party --- ‘No, it’s really her first,’ and I said, ‘No, my daughter was alive for six months.’ — It's still a struggle.”

Some parents discussed how they would establish the memory for their future children: “I will always talk to him about how he had a brother...I will always talk to him about it, show him pictures but that he is with God.”

Other parents compared the deceased and the new baby: “She's not going to replace [deceased baby] you know -- she's just going to be an addition to my family cause she's her own self you know she's gonna come with her own personality”

“I think of her [the deceased] more in the last month that I have in the last 5 or 6 - It's been very, very difficult - a huge reminder, and the worst part is they [new baby and deceased] look identical.”

“I had formed a family in which I had two children ... we have thought about, if the other baby was alive, he would be a year and two months old — this little one even though he would be younger, I believe he would have bossed the other one around because the other baby was very calm -- the one that passed would have been more humble.”

Discussion

The present study adds to our knowledge on parent concerns after losing an infant or child by controlling for data collection at standard time points 7 and 13 months after the infant/child death. Other reports ask for parent recall up to 10 or more years after the loss. In addition, while the majority of research in this area is focused on parents who had a perinatal or newborn death, the present study included parents who lost newborns to children 18 years of age. This study sample included White, Black and Hispanic parents while reported studies are almost exclusively samples of White mothers (DeBackere, Hill, & Kavanaugh, 2008).

Wanting more children yet fear and anxiety about a subsequent pregnancy were the top concerns of parents in each racial/ethnic group and care setting at both 7 and 13 months. Most parents wanted another child but were very scared of having a subsequent pregnancy,

findings consistent with those reported by (Blackmore et al., 2011; Gold et al., 2010; Nazaré et al., 2012). There were more fears and anxiety reported by parents at the 13th month than at the 7th month post the death. By 13 months parents likely had distance from the death and had begun to think about having another child which brought into view their previous experiences around the death. Parents who lost a child in the NICU setting made more comments regarding wanting more children and yet having fear and anxiety about a subsequent pregnancy than those who lost a child in the PICU setting, perhaps due to differences in their life stage. Most PICU families had other children. NICU families all lost infants; PICU families lost preschoolers, a school age child, and an adolescent as well as infants. Parents who did become pregnant feared a pregnancy or newborn loss and sought out practitioners frequently for reassurance especially around the milestones of the previous loss, findings consistent with those of Cote-Arsenault (2003).

Black and Hispanic parents made more comments on praying to God for a subsequent pregnancy and a subsequent pregnancy being God's will compared to White parents. Perhaps this reflects cultural differences reported by Bullock (2011) who found that Blacks are more likely to talk about God's will, be God fearing and believe in a higher power and miracles, findings consistent with the research of Youngblut and Brooten (2013). Additionally, this is consistent with Cowchock et al's (2011) findings that women found religion helpful in coping during subsequent pregnancies.

Study data clearly document parents' feelings about the deceased infant/child as an individual, describing the child's physical features and behaviors. They thought about and kept the memory of the child alive and frequently spoke of sharing the child's memory with subsequent children. Parents also expressed hurt when others seemed to discount the deceased infant/child as one of their children. Comments such as "Don't worry you will have more children and all of this will pass, and the next time you will be a little more cautious" were perceived as hurtful.

Studies document negative health outcomes for mothers (increased risk for death, suicide, psychiatric hospitalization, myocardial infarction, cancers) after an infant or child loss (Espinosa & Evans, 2013; Fang et al. 2011; Li, Johansen, Hansen, & Olsen, 2002; Li, Laursen, Precht, Olsen, & Mortensen, 2005; Li, Precht, Mortensen, & Olsen, 2003; Olsen, Li, & Precht, 2005; Rostila, Saarela, & Kawachi, 2012). A recent study examining health of mothers 13 months following infant/child loss found women had increased hospitalizations for stress related conditions, increased newly diagnosed chronic health conditions (hypertension, angina, asthma, diabetes, heart disease), needed increased doses of prescribed medications, as well as having clinical depression and PTSD (Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013).

Clinical Implications

Assessing parents' history of pregnancy and infant/child loss is important at first and subsequent visits. For parents who have had a loss, are planning a subsequent pregnancy or who may be pregnant it is important to know what they are feeling now about a subsequent pregnancy. Ask them to tell about their loss, when it occurred in gestation or in the child's

life, and what if any events (eg. bleeding, signs and symptoms in the child) led up to the loss. Assess their anxiety (facial expressions, body language) as they talk about a subsequent pregnancy. This is especially important around the time of a previous pregnancy loss. Discuss a plan of what to do should they experience signs or symptoms of possible problems that they encountered around the previous loss. If parents feel they need to contact health providers frequently during a subsequent pregnancy, reassure them that this is acceptable and is common following a loss. Continuous monitoring of their general health is also important as it is for those parents not planning to have another child. Loss of an infant/child is a very significant physical and mental stressor on parents with documented negative health outcomes up to five years after the loss (Youngblut & Brooten, 2012).

In conclusion, assessing parents' subsequent pregnancy plans and recognizing the legitimacy of their fears about another pregnancy are important. Discussing a plan should they encounter problems and carefully monitoring the health of all parents who lost an infant/child is an essential practitioner role.

Acknowledgments

Death in the picu/nicu: parent & family functioning” R01 NR009120.

Funded by: National Institute of Nursing Research, NIH, R01 NR009120

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Table 1
Characteristics of parents (N= 39) who made subsequent pregnancy comments

Characteristic	Mothers (N = 31)	Fathers (N = 8)
Age (M, SD)	31.8 (7.6)	39.0 (10.78)
Race/ethnicity		
Black non-Hispanic	15 (48%)	1 (12%)
White non-Hispanic	9 (29%)	2 (25%)
Hispanic	7 (23%)	5 (63%)
Married or Partnered	25 (81%)	6 (75%)
Education		
< High School	2 (7%)	2 (25%)
High School Graduate	5 (16%)	0
Technical school, Some College	10 (32%)	3 (37.5%)
College Graduate	14 (45%)	3 (37.5%)
Family Income (n = 33)		
<\$20,000	7 (21%)	
\$20,000 to \$49,999	6 (18%)	
\$50,000 and up	15 (46%)	
Missing	5 (15%)	

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Table 2

Themes at 7 Months Post Infant/Child Death

	Hoping for more children	Fear, anxiety, scared	Praying to God	Importance of becoming pregnant for other family members	Keeping the memory of the deceased
Number of Parents responding (N = 31)	11	7	5	5	4
Number of responses (N = 50)	22	12	6	5	5
Gender					
Mothers (n=23)	17 (77%)	9 (75%)	6 (100%)	4 (80%)	5 (100%)
Fathers (n=8)	5 (23%)	3 (25%)	0	1 (20%)	0
Race/ethnicity					
Black (n=7)	7 (32%)	2 (17%)	5 (83%)	3 (60%)	1 (20%)
White (n=10)	14 (64%)	6 (50%)	1 (17%)	2 (40%)	2 (40%)
Hispanic (n=14)	1 (4%)	4 (33%)	0	0	2 (40%)
Care Setting					
NICU (n=22)	17 (77%)	10 (83%)	3 (50%)	4 (80%)	3 (60%)
PICU (n=9)	5 (23%)	2 (17%)	3 (50%)	1 (20%)	2 (40%)

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Table 3

Themes at 13 Months Post Infant/Child Death

	Fear, anxiety, scared to have another child	Wanting another child	Being happy about a new baby	God's will	Thinking about the deceased child
Number of parents responding (N = 27)	9	11	4	6	5
Number of responses (N = 59)	16	15	11	8	9
Gender					
Mothers (n=25)	15 (94%)	14 (93%)	7 (64%)	8 (100%)	7 (78%)
Fathers (n=2)	1 (6%)	1 (7%)	4 (36%)	0	2 (22%)
Race/ethnicity					
Black (n=9)	6 (37%)	1 (7%)	4 (36%)	4 (50%)	3 (33.3%)
White (n=9)	7 (44%)	6 (40%)	4 (36%)	0	3 (33.3%)
Hispanic (n=9)	3 (19%)	8 (53%)	3 (28%)	4 (50%)	3 (33.3%)
Care Setting					
NICU (n=19)	11 (69%)	8 (53%)	8 (73%)	3 (37.5%)	6 (67%)
PICU (n=8)	5 (31%)	7 (47%)	3 (27%)	5 (62.5%)	3 (33%)