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11-27-2016

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Recommended Citation

Brooten, Dorothy; Youngblut, JoAnne M.; Charles, Donna; Roche, Rosa M.; Hidalgo, Ivette; and Malkawi, Fatima, "Death Rituals Reported by White, Black, and Hispanic Parents Following the ICU Death of an Infant or Child" (2016). *Nicole Wertheim College of Nursing and Health Sciences*. 42.

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Published in final edited form as:

J Pediatr Nurs. 2016 ; 31(2): 132–140. doi:10.1016/j.pedn.2015.10.017.

Death Rituals Reported by White, Black, and Hispanic Parents Following the ICU Death of an Infant or Child

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Abstract

Purpose—To examine rituals (disposing remains, wakes, funerals/burials, celebrations) of White, Black, Hispanic parents post ICU infant/child death.

Design and methods—Qualitative design, 63 parents completed English or Spanish semi-structured interviews at 7 & 13 months after infant's/child's death. Interviews were audio-recorded, transcribed verbatim, and entered into Atlas.ti for analysis. An inductive approach to thematization was used to develop codes.

Results—Parents: mean age 35.1 years (SD = 9.03); 33% Black, 27% White, 40% Hispanic; from 17 countries. Three themes emerged: immediately after death - shock and stress, needing help with arrangements, decisions on burial or cremation (conflicts due to finances, religion, culture), when and where to hold wakes, funerals/burials. Wakes and funerals - who prepares child's body, appropriate dress (deceased child, mourners), who can come (cultural restrictions),- variations by child age, parent choice, culture, religion, country. After burial/cremation - being with family, milestone celebrations.

Conclusion—Child death is devastating for parents, other children, grandparents, and family members. Practice Implications. Rituals after child death require decisions about the child's remains, wakes, funerals/burials at time of great pain for parents. This is especially true for newly immigrated parents and those with language barriers where making arrangements is especially hard and often very isolating. Health professionals who provide support need to be cognizant of practice differences based on religion, culture, economics, family traditions, and individual preference and provide as much support and resource as possible. A list of religious leaders representing the community's cultures and funeral service providers who may provide lower cost burials/cremations is helpful.

Keywords

Infant death; Child death; Death rituals; Funerals; Burial; Cremation

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Data have not been reported elsewhere. The funding source had no involvement in the design, data collection, analysis, interpretation or decision on submission of this manuscript.

Background

Ritual Practices after the death of a loved one, including dealing with the deceased's remains, wakes, funerals, burials and gathering celebrations, differ across cultures, religions, race and ethnicity and ages of the deceased. These rituals help those who remain acknowledge the death, deal with their grief, accept the loss, maintain a connection with the deceased, and continue their own functioning (Gudmundsdottir & Chesla, 2006; Weeks, 2004). The most common rituals after death are the wake or viewing, memorial service, funeral or cremation and celebrations of the deceased's life (Reeves, 2011). However, the literature on death rituals is limited; much of it is dated and focuses on adult deaths. Reports of ritual practices after infant or child death are very limited.

The purpose of this qualitative (phenomenology) study was to examine the ritual practices, including dealing with the deceased's remains, wake, funeral, burial and celebrations, of White non-Hispanic, Black non-Hispanic, and Hispanic/Latino parents at 7 and 13 months post the ICU death of an infant or child. Because reports of rituals following child death are so limited providing a context for death rituals requires a review of rituals following adult deaths as well.

Wakes or Viewings

In many cultures after death of a loved one the family holds a wake or viewing of the deceased in the family home, funeral home or in a church prior to the funeral and burial. Ritual practices for wakes or viewings differ by cultures and by generations within a culture. Practices adhered to by older members of the cultural group are often no longer done by younger members. Preparing the deceased's body for wakes or funerals is one example. In the African American and Afro-Caribbean cultures dressing the dead loved one in a respectful way is an important aspect of death rituals. The body is washed, dressed and the hair is groomed by the family. More recently professional undertakers have been given these tasks for many families, especially the younger generation. It is customary to have open caskets for viewing at the wake and/or church service (Moore, 2003). Laying-on of hands, touching, kissing, and conveying one's grief by viewing the remains are important and have been passed down the generations (Holloway, 2002). Food served is as essential as the conversations and recollections that family and friends bring with them to the family home. The tradition of providing meals to the grieving family starts with the wake and concludes with a formal meal after the funeral service.

In the Hispanic culture, dominated by Catholicism, mourning begins with an open casket service, during which a rosary is recited (Clements et al., 2003). Group prayers are done for the soul of the deceased 1 to 2 evenings before the funeral service. Holy water or oil is sprinkled on the body and a pastor is asked to say prayers to guide the deceased (Diaz-Cabello, 2004). The wake or "*velorios*" may be held after the burial where friends and family gather in the house of the deceased or in a near place for 24 hours.

For Mexican-Americans the wake provides a collective sharing of grief and mourning where family members and friends pay their respects to the deceased and offer condolences (Parry & Shen Ryan, 1995). Women lead the prayers, invite family members to attend, and prepare

food and drink for after the wake. Women grieve openly; men do not express their grief or display emotions openly due to the “machismo” tradition.

Funerals or Cremations

Funeral practices also differ widely. Family members and friends in many cultures travel long distances to attend a funeral and provide support to the grieving family (Clements et al., 2003). In the Latino, African American and Afro-Caribbean cultures attending the funeral of family members is considered a family obligation (Schoulte, 2011). For other families newly immigrated to the US, family members may live in the native country and not be able to attend the burial, leaving the newly immigrated family members feeling alone and isolated (Contro, Davies, Larson, & Sourkes, 2010). In many cultures it is customary to stay with the family until after the burial. During burial flowers are thrown on the coffin with kisses in some cultures while in others handfuls of dirt are thrown on the coffin by each family member and friend.

The significance of involving the community in the African American funeral ceremony dates to West African cultures that saw the death and burial as an important, public, elaborate, and lengthy social event (Atkins, 2012; Holloway, 2002). Today elaborate funerals demonstrating the deceased’s importance and worth are common especially for famous, well known people (Hope, 2010). In Black funerals, there is often strong, loud and unrelieved weeping and wailing. There are nurses, the church deaconesses or church mothers dressed in white (sometimes black), who stand near the bereaved family with tissues and fans, ready to aide a mourner or ease the fall of the faint. African American funerals are often hours longer than those of White Americans.

In Jamaica, where African and European religious and cultural traditions have blended, funerals are routinely held 2–3 weeks after the death to provide time for elaborate preparations and for family and friends to arrive (Paul, 2007). Family members of the deceased hold the “nine nights” celebration. People come from miles away singing and dancing to the home of the deceased. Song and drink are central to the 9 night ceremony. Songs are sung 3 days after the death, 9 nights after the death and 40 days after the death by family and friends or by a professional 9 nights singing group (Burrell, 1996). The deceased’s spirit is believed to roam for 40 days; the singing placates the spirit of the deceased.

In accordance with African American beliefs, a body cannot be cremated because it will prevent the soul from going to heaven (Lobar, Youngblut & Brooten, 2006). However, in a comparison of Blacks and Whites, 25 older and 25 middle aged adults were interviewed to assess their views on management of a family member’s body after death (Glass & Samuel, 2011). The investigators found that the use of cremation is becoming more common due to cost and land use. Reasons against cremation were: contrary to religious beliefs; absence of closure; and lack of a sense of place. Moreover, some participants were against it because it was not part of their family traditions.

In the Hispanic culture a church funeral mass is conducted followed by a procession to the grave site where a service is performed. The grave is blessed before burial with holy water

by a priest or deacon. Mexican-American family members make every effort to attend the funeral even if they live far away (Parry & Shen Ryan, 1995). The family expects to have a large funeral to demonstrate how much the individual was esteemed and to demonstrate the strength of the family bond even after death. During the funeral, family members speak of their death and funeral wishes which are left for a sister or daughter to fulfill. During the funeral procession the matriarch or the eldest women enter the church and cemetery first assisted by other women in the family, and then followed by the men (Parry & Shen Ryan, 1995).

In Latino families mourners pay their respects by wearing black or dark colors. During the mourning period immediate family members do not watch television, play the radio, or attend social events; pray “novenas” for 9 days (praying of the rosary is done each day); hold mass for the deceased during the first anniversary of the death and light candles (Clements et al., 2003; Munet-Vilaro, 1998). Family members may go to the grave, cry and have conversations with the dead. In the Dominican Republic during the novena ritual, close relatives of the deceased dress in white or black. The mourning period for older Latino adults may last from months to years.

Infant and Child Death

Research reporting ritual practices after death of an infant or child is very limited. Ritual practices for wakes, funerals, and burials or cremations for an infant or child differ from those practiced for adults and can be influenced by the child’s age, gender, and cause of death. Services are often shorter, there are fewer prayers, cremation may be used more frequently, and often there are fewer family and friends attending and there are fewer family gatherings after burials (Cacciatore & Ong, 2011–2012).

In some cultures, the children are considered pure and innocent and their untimely death guarantees them heavenly status. Filipinos see child death as devastating and parents experience severe guilt (Parry & Shen Ryan, 1995). Rituals are simpler and shorter to lessen family pain; children are considered innocent angels and they go directly to heaven after death. Puerto Rican practices include dressing children in white, face painting to resemble angels and placing flowers outside and inside the coffin (Parkes, Laungani, & Young, 1997). Some cultures bury infants in reserved parts of cemeteries or in exclusively children’s cemeteries. Chinese believe that child death is a “bad death”; parents and grandparents are not expected to attend the funeral; the death is not discussed because it is considered shameful to the family and the gods have not blessed the family (Yick & Gupta, 2002). Family members in many cultures maintain a continuous relationship with the deceased after death (Cacciatore & Flint, 2012; Grout & Romanoff, 2000). For some, this is a belief that life continues after death.

In summary, rituals after the death of a loved one involve dealing with the deceased’s remains, wakes, funerals, burials and gathering celebrations. These practices differ across cultures, religions, race and ethnicity and ages of the deceased. The literature on death rituals is limited; much of it is dated and focuses on adult deaths with very limited reports of ritual practices after infant or child death. The purpose of this qualitative study was to

examine the ritual practices of White non-Hispanic, Black non-Hispanic, and Hispanic/Latino parents at 7 and 13 months post the ICU death of an infant or child.

Methods

The data reported here are from a longitudinal mixed methods study examining parents' health and functioning following the ICU death of a child. The study was approved by the IRBs of 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. Qualitative data were collected from 63 parents at 7 and 13 months post death using semi structured interviews.

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 (bilingual health professional students) called the families, screened for inclusion and exclusion criteria, described the study to them in Spanish or English, answered their questions, obtained verbal consent and scheduled the first data collection visit where written consent was obtained. *Inclusion criteria:* parents were able to understand spoken English or Spanish, had a singleton pregnancy, a neonate who lived for more than 2 hours in the NICU, or a deceased child (18 years or younger) who lived at least 2 hours in the PICU. *Exclusion criteria:* a multiple gestation pregnancy with a deceased newborn, the child living in a foster home before hospitalization, and death of a parent in the illness/injury event, (e.g., motor vehicle crash).

Data Collection

Using a standardized protocol with core questions and probes the 63 semi-structured parent interviews at 7 and 13 months post death were conducted in English and/or Spanish by research assistants (RAs). At 7 month interviews parents were asked for their perspective on events around the time of their child's death. The opening question was "Tell me the story around your child's illness and death." At 13 months parents provided their perspective on their own and their families' lives in the past 6 months since the 7-month interview. The opening question was "Tell me about your life in the last 6 months." Interviews were based on the study purpose, the literature, our clinical expertise, review and discussion with 2 nationally and internationally known study consultants with expertise in qualitative methods and grief in parents of deceased children. Interview questions were reviewed by clinical site coordinators for face validity, understandability and level of language. In addition interview questions were reviewed by other English and Spanish speaking parents for content and readability prior to their use. Interviews were conducted in the parents' homes, were audio-recorded, transcribed verbatim, and compared to audio-recordings for transcription accuracy. Corrected transcripts were entered into Atlas.ti for analysis. An inductive approach to thematization using conventional content analysis (Hsieh & Shannon, 2005) was used to develop initial codes by the investigators and 6 PhD students with relevant

clinical expertise. Using themes derived from this initial inductive analysis and their operational definitions, 2 English speakers and 2 Spanish speakers coded the interviews. Texts that included discussion of “rituals (dealing with the child’s remains, wake, funeral, burial and celebration) practices” were then analyzed.

Results

Sample

All 63 parents (44 mothers, 19 fathers, 47 families) made comments on rituals after their infant or child died. Parent mean age was 32.8 years ($SD = 7.74$) for mothers and 41.4 years ($SD = 8.95$) for fathers. Race/Ethnicity was 34% and 17% Black, 23% and 22% White, and 43% and 61% Hispanic, respectively for mothers and fathers. Most mothers (77%) and fathers (83%) were partnered. Mothers and fathers had completed high school (25%, 11%), some college or technical school (48%, 28%), or college (21%, 44%), respectively. Identified religion was 53% and 44% Protestant/Christian, 35% and 39% Catholic, 7% and 11% Jewish, or 5% and 6% “none,” for mothers and fathers, respectively. While not asked in the demographics for reasons of immigration status, in the interview data parents mentioned their native country as the United States, Mexico, Cuba, Jamaica, Haiti, Puerto Rico, Bahamas, Columbia, Ecuador, Nicaragua, San Salvador, Honduras, Dominican Republic, Peru, Chile, Spain or Russia.

Twenty six percent of the families ($N = 47$) reported annual incomes of less than \$20,000, 28% were between \$20,000 and \$49,999, 46% were \$50,000 and above. Thirty percent of the families had no other living children. Of the 47 deceased children 55% were male; 53% were infants, 21% preschoolers, 9% school age children, and 17% adolescents. Eighteen (38%) died in the NICU and 29 (62%) died in the PICU. Mean age at death was 45.7 months ($SD = 71.08$). Major causes of death were congenital anomalies ($n = 11$, 23%), respiratory conditions ($n = 7$, 15%), infection ($n = 7$, 15%), neurologic conditions ($n = 7$, 15%), prematurity ($n = 6$, 13%), accidental injury ($n = 5$, 11%), genetic disorders ($n = 2$, 4%), cancer ($n = 1$, 2%), and failed resuscitation ($n = 1$, 2%).

While all 63 parents made comments on rituals after their infant or child died, at 7 months post infant/child death 61 of the 63 parents, (44 English speaking, 17 Spanish speaking) commented on “rituals.” At 13 months post the death only 18 parents (14 English speaking, 4 Spanish speaking) did so. Since comments made at 13 months after the death were the same in content as those made at 7 months post the death comments from the 2 time points were combined for the analysis. Parents’ comments fell into 3 areas by time following the death, those made immediately after the infant/child death, those made about wakes and funerals, and those made about activities after the burial/cremation. Parents shared differences in practices in their native land and those done in the US. They also shared differences in practices carried out for children compared to those conducted for adults.

Common Themes Immediately After the Infant's/Child's Death Were: Shock, Stress and Need for Help With Arrangements; to Bury or Cremate and When to Hold Wakes, Funerals, Burials/Cremations

Shock, Stress, Help With Arrangements—Many parents were in shock after the child's death and felt unable to respond to decisions that were needed regarding organ donation, autopsy, what funeral home should receive the body, whether to bury or cremate their child's body, if they could they afford the costs for burial or cremation, where, when and what type of services to hold and where to place the child's remains. For many parents a family member, close friend or member of the clergy stepped in and helped with the arrangements, giving parents options on costs for burial or cremation, potential timing and types of services possible. However for those parents who were recent immigrants to the US and who had language barriers, knowing what to do at this time was very stressful. These parents expressed feeling alone and isolated; their family support systems were in their native country.

Leaving the child's body at the hospital was stressful for some parents. *"They told us, 'Ma'am that's it. You can go and everyone can go home.'"* *"No. How will my daughter stay here upstairs?"* *"No. I am staying until she is buried. We will not leave until we bury our daughter. We will stay until the end because that is our custom."* Another parent said, *"I thought I had to take my baby and be with her and it hurt me a lot to have to leave my baby over there."* One parent commenting on differences in practices in his native country said, *"Someone dies in the hospital, he is taken to the house; so he leaves the hospital in a coffin and everything goes to his house. The house is fixed with an altar; people who accompany the body wake up with it and after 24 hours go to the cemetery."*

Bury or Cremate, When to Hold Wakes, Funerals, Burials/Cremations—A major stressor for many parents was deciding whether to bury or to cremate their child's body. For some parents cremation conflicted with their religion and culture but burial costs were beyond their means. When burial was chosen, where and when to bury the child had to be decided. One funeral home did not charge the parents for the burial since the baby was so small. Parents paid for the coffin and the funeral programs. Burial was done in the parent's native land for one family. For other parents the cost of cremation was beyond their means; some funeral homes did this for no cost. What to do with the child's ashes was problematic for some parents and ranged from burying the ashes in the cemetery, to spreading ashes in the ocean, placing ashes in a urn, in a charm and for one parent placing the ashes in the trash.

Cremation caused conflict or relief for parents. *"If it can be at home which is the normal to handle it at home over there in Mexico, so in that case I would not have cremated my baby. That was what hurt me the most because...due to my economic resources he could not be...buried...simply what we did was cremate him."*

"Cremation is only if.....if the family agree and they gotta be like a lot of family members agree on the cremation because a lot of people don't like their family members to be cremated."

“Um, we immediately knew that we wanted to have her cremated. I didn’t want to see a little box, I didn’t want to pick a place to bury her, God forbid if I ever move away from here and knowing she’s left here. My husband felt the same way.”

Two children had preferences. *“If I die I don’t want you guys to cry; I don’t want to be buried so that the worms eat my body; another way would be better.” “I’d rather be burned.”* A parent commented, *“I just couldn’t bear to put my son in the ground and have worms eat him up. I just couldn’t.”*

“It was hard to scatter the ashes because it was kinda like.....it felt like we’re kinda like letting go of something;and it took us a while to act.....to actually do it; I didn’t wanna do it —she didn’t wanna do itbut then, we finally did it and then.....and it felt a little kinda.....a little better; I don’t wanna say good, but it kinda gives us closure on the whole thing, you know.”

“I’m Catholic so I don’t believe in cremationif I want to burn, I will burn in hell; so I don’t believe in cremation –Um, I had um a traditional Catholic funeral minus being at the church – I had a priest there and everything was anointed and she had a beautiful off-white dress on.”

“We don’t have family here in Florida and we agree that it would be nice for him to be back in Ecuador because our family is there. So we decided to bury him with my father ‘cause maybe in the future, maybe, I don’t know, you don’t know, maybe we gonna be there, you don’t know.”

Common Themes About Wakes and Funerals Were: Who Prepares the Child’s Body, Appropriate Dress and Who Was Allowed to Come; Practice Variations in When and Where to Hold Funerals and Wakes

Who Prepares the Child’s Body, Appropriate Dress and Who Is Allowed to Come—Who prepared the child’s body was important for a number of parents. According to their culture, a member of the family, often the mother washed the infant or child’s body and dressed the child for the wake or viewing. Children were dressed in jeans, polo shirts and sneakers, white communion or baptism clothes to pink frilly dresses.

Overwhelmingly, parents reported that wearing the appropriate traditional colored clothing (black, white, grey, dark colors) was important and showed respect for the family and the deceased. For a few parents doing otherwise signified disrespect. However, a number of parents requested family and friends wear bright or lighter colored clothing since the death was an infant or child. These parents focused on celebrating the life of the child who had no sins rather than the somber praying for the soul of the adult. *“Me and Daddy always talking about how old is she – when it is time for prom gonna have her in a lavender dress – so that’s the color we picked out for her home going, and everybody showed up in that color - their lavender and white. It was so nice.”*

Wakes and funerals were generally open to all family, friends and neighbors. In some families parents reported that pregnant women and little children were not allowed at both wakes and funerals. Often the reasons for the restrictions were not clear and had been passed

down and enforced by older family members. Parents appreciated doctors, nurses and other health care workers attending the services.

“Apparently in Haiti, if you are a young mother and you lose a child, you’re not supposed to go to the funeral or go to the cemetery and so that was an issue that came up – that they didn’t want me to go; apparently their belief is if you bury one or if you go to the cemetery... take one to the cemetery, you’ll be taking all your other kids to the cemetery. So a lot of older Haitians – all the moms was –telling my mom not to let me go to the cemetery.”

Practice Variations in When and Where to Hold Funerals and Wakes—Where, when and what type of services to hold had to be decided by the parents. A wake or viewing before a church service was common for parents in this study. For some families, parents or a family member had to be with the child’s body until the burial. For others a wake was eliminated since this was the death of a child. Some parents held the wake over several nights, and it was viewed as an opportunity for family and friends to come and comfort them. Usually the wake was held the night before the funeral service. Some parents negotiated longer hours, food and drink for those who came as was the custom in their native country. Funeral services, held in a church, chapel or in the parent’s home were shortened since this was death of an infant or child who was considered innocent (no sins) and thus did not require the usual prayers. In death, the infant or child was “an angel”. A few parents insisted on lengthy services for their infant or child. *“He had no sins; he’s an angel you don’t have to pray - you don’t have to do all – you don’t have to do masses and stuff. You got to give thanks to God that you have an angel and that’s what keep me going every day.”* Other parents had masses conducted. *“The kind of Mass we did was called ‘Mass of the Angels’ and it’s a specific funeral Mass for babies. The priest wears white for purity or whatever and it’s more of a celebration of life rather than the dark the black – the gloom of a normal funeral.”*

Wakes and funeral services varied but celebrated the child’s likes. *“Well I was born Catholic, but I did it very Christian – non-denominational; we got hip-hop music, beautiful pictures of her; we did a candle light – a release of balloons and everybody talked about my daughter - what they can remember of the happy times and the crazy she did.”* Other parents shared their daughter’s love of butterflies, *“Well she liked butterflies; we let them, you know, the butterflies go - it’s such a beautiful thing; to me it was kinda like what happened to her – I mean, you let these butterflies go and they are free and they fly up and fly away and that’s what you know ... she passed away and her spirit left her body and she flew away into heaven.”*

Parents appreciated doctors and nurses attending the services. *“Her doctors came in from New York which was incredible surprising; her radiation nurse came in - it was unreal - they took good care of her, so we now have to give back to them in honor of her.”*

Presentation of the infant’s or child’s body was a concern for parents. *“Well the funeral – basically it was nice. It wasn’t sad because the funeral home put her in a bassinet – she wasn’t in a coffin, so it wasn’t that sad because she look like a doll baby.”*

Some parents were very overwhelmed by people and activities while others were saddened when family members were unable to attend. One parent said, *“I didn’t even have a chance to say I wanna be alone - people were taking the day off coming by; the phone ringing nonstop; the door didn’t even stay closed. People were just here.”* Another parent said, *“I cut my phone off for like that whole week ‘cause ... I didn’t want nobody telling me anything, I didn’t want to hear ‘It’s gonna be ok.’ I didn’t want to hear that it happen for a reason, I didn’t want to hear ‘God knows best.’ I didn’t want to hear any of that stuff.”*

A few parents offered suggestions to help avoid being overwhelmed whenever possible. *“A Rabbi recommended –that we make all the arrangements before, so when we actually, you know ... after she passes, it’s not as overwhelming. I felt like that was a very good suggestion. Don’t wait until last minute because you’re dealing with so much and the whole family comes; you’re co-coordinating all this stuff.”*

Taking pictures helped some families feel part of the activities. *“His aunts from the Dominican Republic couldn’t make it so they wanted pictures, so I had my sister hire a photographer and take pictures of ... which is kinda morbid but that’s what they wanted and that was fine.”*

Parents also reflected on the differences in practices for wakes and funeral services in the US and in their native country. A number of parents commented that in their native land the funeral procession went through the town with the coffin past places where the deceased had been or lived (as the deceased’s last visit) and then carried the coffin to the cemetery. Family and friends walked behind the casket often accompanied by singing, praying and music. Others commented *“When someone dies in Haiti, they’ll take longer to do the service or planning because people have to come in from the States or come in from Canada or wherever they’re living.”*

“Everything in Peru is quick. I mean when someone dies, the entire transaction cannot last more than 3 days according to law. Where the wake is – you go – it is like a place ... a club ... cofia. For example the military have a special place – the marines have a special site ... teachers have a special place. When they say someone passed away ... you already know where they [deceased] are ... all of the family members, all of the friends go. I mean you can’t not go, I mean, it is mandatory. They take flowers and flowers and flowers and flowers and flowers ... and it is the custom to always have coffee and cookies, always, always ... the wake site gives you that. It is customary for the person to be buried and then comes ... second stage of the masses; everybody has to go to the mass of 7 days; then there is the mass of the month, and then a mass of the year. And in all these masses a meal is offered. And you have to have keepsakes made to give them out as gifts.”

Another parent contrasted the US with his country. *“You have to go to the wake and the funeral. And you get the permission from work. So you say ‘such person has died’ ok you get hours and all ... I mean it is good ... it is something ... it is part of the culture; there people have more time. Here with the theme of work and studying and many other things, there is no time.”*

Common Themes After the Burial/Cremation Were Being With the Family, Celebrating Milestones of the Death and Holidays

Being With the Family—Following the burial, funeral service, or service to celebrate the child’s life, family and friends came together for a “gathering” with food and drink in the parents’ home, a family member’s home or in a restaurant. Practices over the next week or 2 following the burial varied by culture and religion. In some cultures family members remained with the parents for a week or more until the parents were capable of functioning. Some parents just wanted to be alone. Jewish families sat Shiva (traditional 7 day mourning period in the home after the funeral) and friends came to comfort the parents. *“You choose how long you sit Shiva but it’s ... depending on how religious you are – people who are sitting Shiva are immediate family – the parents, any brothers and sisters, not the grandparents, not the nieces. At the funeral they give you a black ribbon to wear and they cut the black ribbon to show that there’s a tear in your heart that can never be replaced and you wear that for thirty days and then ... you’re not allowed to do things for yourself, you’re not allowed to go get yourself food or get yourself a glass of water or things like that; someone in the house does that for you. It’s a time where people come to the house to spend time with you, be there for you, talk about stories whatever; you set certain times – from like nine in the morning to seven at night. It can be like three days, four days or seven days; people send food – so much food.”* Another Jewish mother commented, *“I was supposed to do an unveiling with the (head) stone. I didn’t do anything – I just had the stone done and I went to look at it and that was it.”* Catholic parents honored the 9 days of praying (novenas). Others reported keeping their child’s remains close.

“We brought her home (ashes) - which was hard; going and getting her was very hard but, ah, we just stuck her on the shelf which sounds really dumb or sounds really bad when you say it like that, but I did need to bring home my child, that’s what I did – that’s what I think about and I don’t have to go see her, she’s there all the time. I’ll probably do something when she’s 18 - because 18-year-olds want to go see the world and travel. Maybe I’ll go do something then but for now she’ll ... she’ll stay here with us.”

Celebrating Milestones of the Death and Holidays—Some parents conducted prayers and activities on the deceased child’s birthday, on certain months after, and on the 1 year anniversary of the child’s death.

“I think it’s more Dominican because, um, I saw it growing up. I saw it done and is a holy hour where, um, you pray for the person’s soul; so it’s a solid hour of praying after the nine days on the specific day of the person’s death for the first year, you do a holy hour of prayer; in our case what we do is go to mass together as a family on that day, whether it’s a Monday or Friday, whatever, and I do the rosary. The front door is closed, no one is allowed to open like to walk in or out the front door until the ninth day where the front door is open.”

“So, the day of the dead, you make an offering to them that day. In Mexico you make an altar, all of that when they are dead. I sent pictures to my parents because they never met the baby; the pictures it did hurt them ... they got sad; so I told

them to place sweets on his altar because on the altar in Mexico for each person they put food. If it is an older person they put a glass of water, salt, and food. If the person liked to smoke they leave a cigar. If they liked to drink they put a glass of tequila ... like that. And in that case when they are little babies ... I told my mom to put sweets, little toys. She bought little cars. Put his picture and she played there with a car because – our idea is this, that when there is a dead person and you place an offering there, the people get close to the offering, and they feel that it really is the [dead] person that is there near the offering ... visiting the offering. So what my mom did was ... she started to play there with the car on top of the offering thinking the baby was there.”

Parents shared their continuing grief and many a belief in a later meeting with their child.

“I’m never gonna replace my daughter no matter if I have a hundred kids, that one daughter is never gonna be replaced.” “I always say she pass away on the 13th for me, ‘cause that was the last time I talked to her but her death certificate says the 23rd.”

“When Christmas came I had brought her a gift and everything so it was like ... everything was ok but then I’m like, ‘Ok,’ I had to set my mind so – like she’s back at the hospital ‘cause to this day I’m not ready to deal with it and I’m not ready to let go and I’m not ready to understand that she’s gone. So I got my mind set real strong that she’s in the hospital and I just feel like she’s isolated to where I can’t see her; she’s here but she’s just at the hospital and I can’t see her no more but I know she’s there and a lot a times I call [hospital name] just to hear the automated service and just to hear ... I ask for the NICU and just to hear them pick up and say NICU and then I hang up –.”

“I believe that one day I will see her again and through her life me and my husband feel that we are gonna start sort of like a hospital of some sort in Haiti for other children who has medical problems so I feel that maybe that was her purpose.”

Discussion

A child’s death is very painful and difficult for most parents and family members across cultures and religions (Youngblut & Brooten, 2012). Study data captured the stress and complexity of decisions experienced by parents including making arrangements for the infant’s/child’s remains, when and where to hold wakes, funeral services, decisions on burial or cremation. Parents had to decide who should be told about the death, how and by whom. Their decisions were influenced by finances, religion, culture, and family traditions. Parents had to make these decisions as they handled their own pain and grief and that of their other children, grandparents, other family members and friends. Parents often agonized about where to bury the infant’s or child’s remains or whether to use cremation, choices tempered by finances, traditions or religious practices. For newly immigrated parents and for those with language barriers, making arrangements was especially hard and often very isolating. These parents were familiar with practices in their native land but were not familiar with the practices and laws in the US. US-born parents often found themselves dealing with or in conflict with traditional country or religious practices held dear by their older relatives. The

reasoning behind such practices was often forgotten but added stress for the grieving parents.

Parents welcomed assistance from friends, family and health care providers in making final arrangements. Help especially from health care providers in these matters was valued, findings consistent with that reported by Brooten, Youngblut, Seagrave, et al 2013. Some parents who expected the child's death found that making arrangements ahead of the death was very helpful in dealing with decisions at the time of the death. Some children let their wishes for a burial or cremation known, allowing parents to fulfill the child's wishes. For other parents having a family member or friend manage visits from relatives, friends, and community members helped the parents get the rest and quiet they required. This was especially true for parents who had maintained hospital vigils during the infant's/child's last days and weeks.

Study data also documented the differences in ritual practices conducted for infants and children compared to those for adults. Services were often shorter, there were fewer prayers, cremation was used frequently, and often there were fewer family and friends attending the rituals and gatherings, data consistent with the research of Cacciatore and Ong (2011–2012). Deceased infants and children were dressed in a wide variety of colors and types of clothing from jeans and T-shirts to frilly white dresses. Some parents requested mourners to dress in light or bright colors rather than the traditional black or dark colors. Infant and child death also represented loss of parenthood, loss of a future with that child and experiencing his/her development and milestones, and for many, loss of someone to carry on the family name. Loss of this magnitude holds potential to have devastating physical and mental health effects on parents over the first year after the death and beyond (Youngblut, Brooten, Cantwell, delMoral, & Totapally, 2013; Fang, Fall, Sparen, et al., 2011). Monitoring the health of these parents over time is important for the health of both the parents and the family.

Clinical Nursing Implications

When caring for parents who have lost an infant or child, assess parents' individual needs and cultural customs since these may differ from individual to individual and from generation to generation within the same culture. Consult with the bereavement team and consider attending the child's memorial services if feasible since parents appreciate such support from nurses and other health care professionals. Send a condolence card following the child's death and at the 1 year anniversary of the child's death. Since many nurses are uncomfortable dealing with death, especially a child's death, attending formal training in end-of-life care and serving as a member of the bereavement team can be very helpful for nurses in providing support to parents. As part of that effort, having a list of religious leaders representing the cultures in the community and funeral service providers who may provide lower-cost burials/cremations can be very helpful to parents during this stressful time.

In conclusion, death of an infant or child is devastating for parents, other children, grandparents and family members. Rituals after the death require decisions that are stressful and complex at a time of great pain for the parents and family members. It is important for health care professionals who provide support to be cognizant of differences in these

practices based on religion, culture, economics, family traditions and individual preference and to provide as much support and resource as possible.

Acknowledgments

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

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