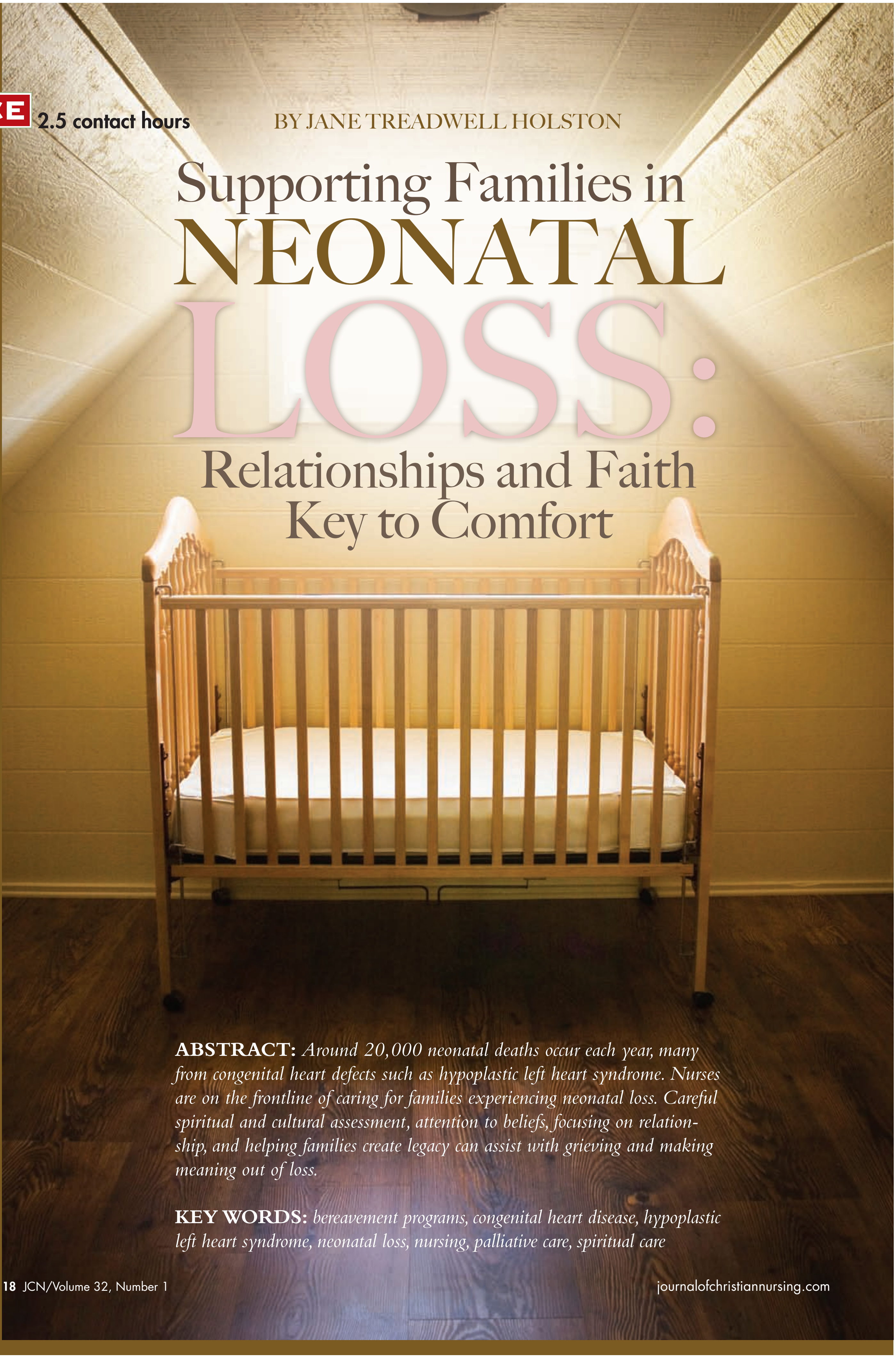


CE 2.5 contact hours

BY JANE TREADWELL HOLSTON

Supporting Families in NEONATAL LOSS: Relationships and Faith Key to Comfort

ABSTRACT: *Around 20,000 neonatal deaths occur each year, many from congenital heart defects such as hypoplastic left heart syndrome. Nurses are on the frontline of caring for families experiencing neonatal loss. Careful spiritual and cultural assessment, attention to beliefs, focusing on relationship, and helping families create legacy can assist with grieving and making meaning out of loss.*

KEY WORDS: *bereavement programs, congenital heart disease, hypoplastic left heart syndrome, neonatal loss, nursing, palliative care, spiritual care*

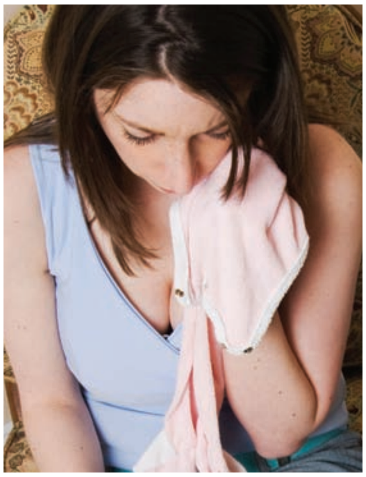
REGAN'S STORY

It was a beautiful day in March. Elizabeth* was getting ready to deliver her second child, a little girl named Regan. Earlier in Elizabeth's pregnancy, she and her husband, Art,* learned that Regan had hypoplastic left heart syndrome (HLHS), a congenital anomaly where the left side of the heart fails to properly develop (see sidebar). As a result, Elizabeth and Art had been faced with difficult decisions. HLHS is incompatible with life; therefore, if Regan were to have any chance of survival, she would need numerous medical and surgical interventions followed by a lifetime of potential complications. Without intervention, Regan's life expectancy would be 1 to 2 weeks. After much prayer and consideration, Elizabeth and Art decided to carry the pregnancy to term and after delivery, keep Regan as contented as possible and allow her to spend her short time on earth comfortable and surrounded by loving family and friends.

Many developments have taken place in neonatal care, including repair of HLHS, since Regan was born in 2002. However, Elizabeth and Art's experience and recounting of what helped them, remains relevant today. They share their story to help nurses offer compassionate care to other families facing neonatal loss.

From their spiritual assessment on the admission history and physical, we were aware that Elizabeth and Art professed Christian faith. Their faith assured them their daughter would leave this world and enter heaven alive and well (1 Corinthians 15). Their actions speak to the importance of faith and how God can sustain us through even our darkest times.

As a nurse who specialized in caring for families experiencing the loss of their baby, I had the privilege of meeting Elizabeth and Art the morning of Regan's birth in Elizabeth's room. The neonatologist and I met with the parents to discuss what they could expect during and after Regan's delivery. Elizabeth informed us she did not want Regan to be subjected to any painful interventions. She also did not want any pictures of Regan for fear that looking back would be too painful. I gently assured her that, based on my training and past experience, she might consider allowing us to take a few pictures. She could then later choose whether she wanted to keep pictures. We answered the couple's questions and left the room, allowing them time alone to prepare for the birth of their child.



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Regan's story highlights the critical nature of *relationships* in providing care to families whose baby dies.

GENTLE SUPPORT

After several hours of labor, Elizabeth delivered her precious baby girl. Regan was full term, beautiful, and aside from turning slightly blue when she cried, appeared healthy. After being held by family members, I gently bathed and dressed Regan. I wrapped her in a warm blanket and placed her in her mother's arms, where she would spend most of the next 6 days.

Once Elizabeth was discharged, she and Art stayed with Regan in a parenting room in the neonatal intensive care unit (NICU). My nursing role mainly consisted of regular checks on Elizabeth and Regan and providing comfort measures for them both. My co-workers and I assisted with feeding, bathing, dressing, and changing Regan's diapers as needed. While carrying out these tasks, we talked, laughed, cried, and prayed. Our presence was the most important aspect of care we could offer. Regan appeared to be healthy except when she exerted herself. When she became active with her baths she would turn a dark bluish, purple color; when she drank from her bottle, she developed circumoral cyanosis. Otherwise, only slight deterioration in her oxygenation could be seen from one day to the next.

As a way to support families with babies in the NICU, nurses kept diaries from the babies' perspectives for parents to take home after discharge or death. Daily progress and events are recorded in the diaries. Excerpts from Regan's diary that I kept during our time together are in Table 1. Elizabeth says this diary remains dear to her years after Regan's short life.

On day 6 of Regan's life, I received an early morning call from the NICU. Elizabeth awoke around 3:30 a.m. to find Regan had died peacefully in her arms while they both slept. I arrived

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*Names of the parents changed; Regan's name was kept at the parents' request.

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at the hospital shortly after receiving the news, to find Elizabeth holding her daughter. Elizabeth and I gently bathed Regan for the last time. We dressed her in a gorgeous pink gown and bonnet. I assembled a handmade memory box that contained Regan's diary, her tiny hand and foot prints, a lock of hair, a tiny gold ring, a stuffed lamb, a book entitled, *Mommy Please Don't Cry,* with a special handwritten message inside, and Regan's hospital identification bracelets. These memories, along with the many pictures Elizabeth and her family took of Regan, make up the bittersweet memories they hold close to their hearts.

HARD DECISIONS, SUPPORTIVE CARE

After learning of Regan's diagnosis, Elizabeth and Art spent hours researching HLHS, talking with healthcare providers, praying, and processing with their families. When considering the risks and demands associated with each surgery back in 2002, and the long-term sequela Regan could face, Elizabeth and Art elected to provide comfort care instead of surgical intervention. During Elizabeth's pregnancy, she prayed Regan would go peacefully and not suffer. She believed God answered her prayer by giving her 6 priceless, tranquil days with her daughter.

Because of our hospital bereavement program, I maintained contact with Elizabeth after Regan's death. Elizabeth told me God supplied every need she and her family had and she could feel God's presence at all times. She felt God began preparing her for this challenge long before Regan was born. For example, shortly after learning of Regan's condition, Elizabeth was at a Bible study where a woman spoke about her infant daughter who had almost died. The woman commented she was not sure why she was telling her story but felt God led her to as perhaps someone needed to hear what she had to say. Afterwards, Elizabeth explained her situation. A friendship was formed, and Elizabeth had a special friend to help her prepare for the coming difficult days. Having someone outside the family who understood what she was going through and in whom she could confide was a gift.

Additional coping strategies included spending more time with family and cherishing their 2-year-old son. Art and Elizabeth's focus changed from preparing to bring a baby home to strengthening their existing family through the birth, life, and death of a precious baby girl. Elizabeth latched onto daily devotionals that seemed to speak directly to her. The more she relied on God, the more comfort she received. She found that during her most difficult days, she could come to God, listen for his voice, and receive his comfort in the midst of her anguish.

Elizabeth recalls that she never felt she was bothering anyone or was in the way at the hospital. Her requests were carried out with patience and tender care. As caregivers, we were mindful of the fact that grieving families are spending the most difficult time of their lives in an unfamiliar environment. It is in those times as Christians that we are called to be the hands and feet of Christ, his arms that hold, and his voice that comforts (2 Corinthians 1:3-5; Galatians 6:9). Members of the healthcare team included the family in every aspect of Regan's care. Anticipatory guidance was used to educate so they would know what to expect as Regan's condition deteriorated.

NURSING CARE IN NEONATAL LOSS

Sadly, around 20,000 neonatal deaths (within the first 28 days of life) occur each year in the United States, where 1 in 125 babies is born with a heart defect. Heart defects account

Table 1: Regan's Diary

Day 1: Hello, Mommy and Daddy! Today is my birthday! I'm so glad to finally get to meet you. I know you are sad that I will not be with you for very long, but I am looking forward to our time together. I spent my first day getting cleaned up, dressed in a pretty gown, and being held and loved by my family. What more could a girl ask for?

Day 2: Today was a big day! After snuggling with mommy all night, Nurse Jane gave me a bath. I love my baths! I especially love the part where she washes my hair. The warm water feels so good! She dressed me in a beautiful white christening gown and bonnet. My grandmother gave me a gorgeous cross necklace. I look so pretty! We all went to the hospital chapel and I was baptized. I feel so blessed to have such a wonderful and loving family.

Day 3: I had another perfect start to my day. After a nice warm bath, we got to move to our new room across from the NICU so I could be close to my nurses and doctors but still be with you and Daddy. My grandparents held me and loved on me all day. It was such a special day!

Day 4: My aunt had made me a pretty dress and I could not wait to put it on. Everyone said I look pretty in pink. I enjoyed another quiet and peaceful day in the arms of my loving family. My aunts, uncles, and grandparents love me so much!

Day 5: My nurses keep checking on me. They say I look beautiful. It must be true Mommy, because you keep telling me that I am the most beautiful little girl that you have ever seen!

Day 6: Mommy, last night was the most special one yet. I fell asleep in your arms and woke up in the arms of Jesus. Heaven is such a wonderful place! It was a perfect ending to my short life on earth. I thank you so much for the most precious gift anyone could possibly give—the gift of life and love.

for 25% of infant deaths, where many of those who die in the first month of life have HLHS (March of Dimes, 2010). Hospitals can provide much-needed support for parents who suffer the loss of an infant through bereavement programs. Families who report having positive experiences at the time of their loss demonstrate a healthier progression through the grief process, as opposed to those who report bad or unpleasant experiences. Compassionate and caring nurses who keep families involved and informed have been cited as contributing to a positive experience, whereas insensitive and unsupportive staff can create an unpleasant experience and contribute to parents' grief (Brooten et al., 2013;Gold, Dalton, & Schwenk, 2013; Kendall & Guo, 2008).

Regan's story highlights the critical nature of *relationships* in providing care to families whose newborn dies (Limbo & Kobler, 2010). Parents report that a crucial aspect of care is nurses' physical presence and "bearing witness" to their experience (Rosenbaum, Smith, & Zollfrank, 2011). Being there for and with parents is essential. A tender touch, a simple, "I'm sorry," or just sitting quietly can be the most appropriate approach. Caregivers should refrain from remarks such as, "He/she is in a better place," "It was God's will," and "I know how you feel." Although well intentioned, statements trying to explain why the unexplainable happened are offensive.

Staff can make a difference for families by providing information, discussing all options and offering choices, and sensitively knowing how to relay information without overload. Understand that families need time to process and make difficult decisions before and after death, and that small decisions can seem insurmountable. Families want staff members to be present, or absent, when needed. They want time and space for privacy while knowing nursing staff can be quickly present. Privacy means real seclusion, not just pulling a curtain or putting up a screen, as well as being sensitive to location and activities going on near the family. Overhearing celebrations of other families is heartbreaking for those experiencing loss; thus, providing as much privacy as possible is critical (Brooten et al., 2013; Gold et al., 2013; Limbo & Kobler, 2014; Stokowski, 2004).

Details such as calling their baby by name and working for continuity of care is priceless. Placing an anonymous card on the door of a bereaved mother's room alerting staff to circumstances can help prevent uncomfortable situations. Making sure all caregivers during and between shifts are aware of the smallest details offers loving sensitivity. Using the right gentle touch or tone assures presence is meaningful and not a hindrance. Inviting family members into physical care of the infant and being there to guide them has been found helpful to the grieving process (Milstein, 2003; Rosenbaum et al., 2011). Preserving keepsakes for the family to choose to take home is typically appreciated. Offering further contact if the family wishes, as well as suggestions to get in touch with the hospital chaplain, social worker, their personal clergy, or friends may be helpful in moments of crisis. Being familiar with hospital protocols contributes to smooth and seamless care (Stokowski, 2004).

> Our presence was the most important aspect of care we could offer.

SPIRITUAL CARE

Families relay that spirituality is paramount as they attempt to find meaning in the death of their child. Many parents find meaning through belief in God that gives hope, and accepting that there is a higher purpose to their child's life and death (Milstein, 2003; Rosenbaum et al., 2011).

Interactions that invite families to share their beliefs and struggles can be a first step in offering spiritual care. Acknowledging their pain and then asking parents open-ended questions such as, "What is helping you cope?" or "What is it you most hope for?" can help families process their feelings and beliefs. If parents have unrealistic beliefs or are hoping for a miracle, ongoing open dialogue is crucial. Validating their beliefs while helping parents understand their infant's diagnosis and prognosis is invaluable, as parents watchfully wait for their child to be healed or die. Over time, helping families reframe their thinking can be extremely beneficial. For example, helping parents realize that if their child goes to be with God, or that they will see him or her again in heaven, also is a miracle (Rosenbaum et al., 2011). Giving parents time and space as needed is necessary for them to move forward with decision-making.

Religion and religious rituals help provide order to life and death experiences, facilitate personal relationships with a divine power outside the self, and offer beliefs about the afterlife. Accommodating families' religious beliefs and rituals is important to good spiritual care. Families report that faith, prayer with staff, and care from clergy were comforting in their baby's end-of-life care (Rosenbaum et al., 2011).

Reflecting, Elizabeth recalls that during her pregnancy, her time with Regan, and in the days following Regan's death, God met her needs by providing the right people at the right time. When she first entered the hospital, she felt God's care as compassionate staff members met their needs. I prayed with Elizabeth during Regan's hospitalization. I, along with nurses, physicians, and the hospital chaplain, attended Regan's baptism performed by the family's clergyman.

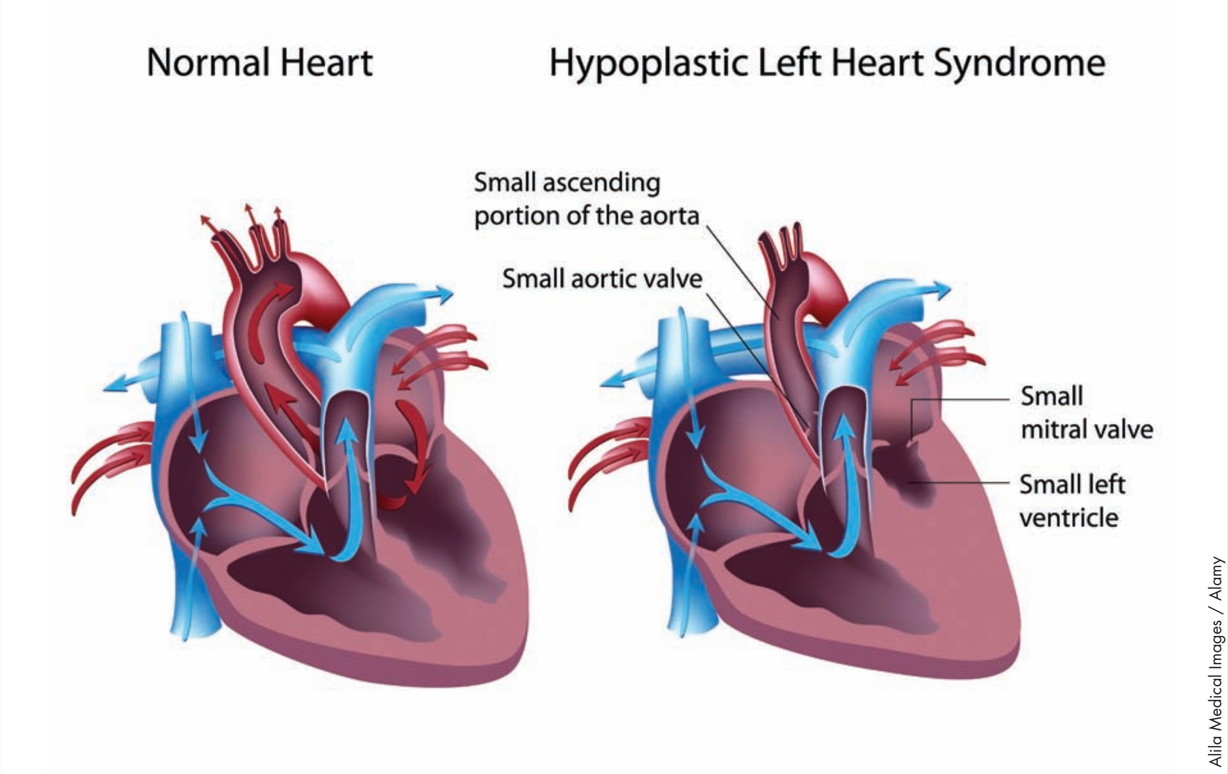
Understanding Hypoplastic Left Heart Syndrome

Hypoplastic left heart syndrome (HLHS) is a rare, congenital disorder that occurs when the left side of the heart fails to properly develop in utero. In HLHS the left ventricle is undersized, the mitral and aortic valves are not formed or are very small, and the ascending portion of the aorta is underdeveloped—all resulting in no or little blood flow from the left side of the heart. Often these babies have an atrial septal defect. Hypoplastic left heart syndrome occurs in about 960 babies in the United States each year, or 1 out of every 4,344 births. Approximately 10% of patients with HLHS have other birth defects. The etiology of HLHS is unknown. The condition is typically diagnosed during pregnancy or shortly after birth (Centers for Disease Control and Prevention [CDC], 2014).

Symptoms of HLHS include central cyanosis, lethargy, pounding heart, weak pulse, tachypnea, tachycardia, poor suckling and feeding, coolness of the extremities, an abnormal electrocardiogram, abnormal heart sounds, weak peripheral pulses, and an enlarged liver (CDC, 2014; National Library of Medicine MedlinePlus [NLM], 2013). These worsen as the patent *ductus arteriosus* and *foramen ovale*, normal openings in utero between the left and right sides of the heart, begin to close after birth.

Treatment options include surgery to repair the defect(s), heart transplant, or compassionate care with death typically occurring within the first week of life. If treatment is chosen, the infant will be started on prostaglandins to help prevent the ductus arteriosus from closing, and they will be intubated shortly after birth, especially if breathing difficulties arise. Cardiac catheterization and/or surgery may be performed to maintain an open foramen ovale or atrial septal defect. Medications may be used to lower blood pressure, and treat heart failure and fluid overload. High calorie formula and/or a feeding tube are used to compensate for poor feeding. Over time, these infants can develop chronic diarrhea from protein losing enteropathy (CDC, 2014; NLM, 2013).

Surgical repair involves a series of three surgeries. Stage I using a Norwood or Hybrid procedure is performed within the first 2 weeks of life to shunt blood to the pulmonary arteries to maintain pulmonary blood flow, and to help the right ventricle pump blood to the lungs and the body. Infants with other complications (i.e., <2.5 kg weight, prematurity, other birth defects) have a surgical mortality rate over 60% (Holoshitz, Kenny, & Hijazi, 2014). Stage II, the bidirectional Glenn Shunt or Hemi-Fontan procedure, is typically done at 4 to 6 months of age. The major vein carrying deoxygenated blood from the superior vena cava and upper body is connected to the pulmonary arteries, which decreases workload on the right ventricle and allows blood returning from the upper body to go directly to the lung. Stage III, the Fontan procedure, is performed between



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18 months and 3 years. The vessels of the inferior vena cava are connected to the pulmonary vessels, allowing blood returning from the lower body to go directly to the lungs. The single functioning right ventricle now supplies blood only to the body. Cyanosis should resolve because oxygenated and deoxygenated blood no longer mixes (CDC, 2014; NLM, 2013).

The 5-year survival rate for this staged surgical approach is 70% to 75% (NLM, 2013; Ohye, Mosca, & Bove, 2012), and is greatly dependent on the size and function of the right ventricle and the presence of other anomalies. Surgical procedures do not cure the underlying problems with the left heart; HLHS patients will need cardiac care the rest of their life and even a heart transplant. More surgeries may be needed during early adulthood to correct arrhythmias or other complications.

Cardiac Transplantation. Even though transplant is associated with a lower mortality rate, only about 75% of infants on the transplant waiting list receive donor hearts. These patients endure a lifetime risk of rejection, require immunosuppressive drugs, and have an increased risk of infection (Ohye et al., 2012).

Regardless of which treatment option is chosen, HLHS patients typically are limited physically; experience decreased endurance; have an increased risk for arrhythmias, edema, emboli, and neurodevelopmental problems; and may require additional cardiac surgery (Mayo Clinic, 2012).

Compassionate Care. Parents who do not want their child to suffer may opt to forgo treatment, choosing instead to make the most of the short time they have with their infant. This option is not as much of a drain (cost, time, leave from work, etc.) as surgical intervention. As the foramen ovale between the right and left atria closes, blood flow from the left to the right side of the heart shuts down and little or no blood is pumped from the left side. As the ductus arteriosis between the aorta and pulmonary artery closes, blood supply to the body is cut off and the infant dies.

> Although well intentioned, statements trying to explain why the unexplainable happened can be perceived as insensitive or offensive.

CREATING LEGACY

Recording the story of an infant who dies helps family members maintain memories and connections with their infant. Creating a legacy can assist with attachment and bonding issues important to the grieving process, as well as help family members accept the reality of death (Ives-Baines, 2010; Limbo & Kobler, 2014). Legacy-making helps parents honor the life of their baby, tells the baby's story, and reminds parents how much their child was loved. A gentle suggestion to take pictures of the infant or start a memory box may begin with, "Have you thought about…?" or "How would you feel about…?" You might also say, "Some parents I've worked with found this to be helpful. What about you?" Avoid language such as, "You'll regret it later if you don't…." It is fine to offer an option more than once, as long as one remains respectful that "no" can mean "no" and avoids being coercive (Limbo & Kobler, 2010). Parents are experiencing such raw grief at the time of the loss that often they cannot imagine wanting to relive those moments. However, after time has passed, they may find themselves trying to remember every detail of their baby and the events surrounding their precious little one. Informed consent or dissent to your offers to activities should be documented in the healthcare record (Ives-Baines, 2010).

A mother who suffered the loss of a newborn where I work told a member of the family support team that the hardest part of her experience was leaving the hospital empty-handed. Now, soft, stuffed lambs are provided for mothers whose arms ache to hold their babies. The lambs have ribbons around their necks with a small card that reads: "I cannot replace your baby, but when you need something to hold, I am here." New mothers have been seen lying in their hospital beds clutching these lambs, or being wheeled out at discharge holding their lambs in their laps. Volunteer groups who offer services such as making gowns, bonnets, blankets, and memory boxes can help defray costs of bereavement programs to hospitals. Additional legacy-making activities are offered in Table 2.

Rituals can be helpful in assisting families to create a legacy. Rituals can include baptizing the infant, a naming ceremony, or a celebration of life ceremony. These can be planned or impromptu with prepared statements or spontaneous remarks, and can include all members of the family from children to extended family, along with clergy, friends, and healthcare staff. If an infant has been intubated on a ventilator and the decision is made to extubate and allow death, a ceremony making this sad event sacred can add meaning to the loss.

It is important to note that in Western culture, the care described above is widely accepted. However, families from other cultures may have different views on how infant death should be handled. It is imperative that a cultural and spiritual assessment be performed, and that staff members are aware of special needs or requests (Kendall & Guo, 2008). Nurses need to take as many cues from the parents as possible. Holding a deceased infant, taking photographs, preserving locks of hair, involving siblings, and other options should be gently offered and never forced. Even when families say they do not want to engage in an activity, if offered sensitively, legacy-making can show caring and compassion.

Legacy-making also is helpful to healthcare staff members, as it offers a way to meaningfully care for families when nothing can be done to save their infant. Legacy-making with families can help staff openly process their grief (Ives-Baines, 2010). Staff members also can engage in remembrance ceremonies or debriefing sessions. Stopping to reflect and acknowledge losses is helpful. A moment of meditation and/or prayer before or after shift report, a memory book or memory wall staff contribute to, or making handprints in sand or with finger paint to commemorate the team's participation in a child's life can be quite meaningful (Limbo & Kobler, 2014).

BEREAVEMENT PROGRAMS

Bereavement programs impact how infant loss is perceived and/or handled by the family. Programs that include counseling for families before, during, and after the loss; assurance of privacy for the family; offering a chance for families to see and hold their infant; and making sure that memories are created have been described as most helpful (Kendall & Guo, 2008; Limbo and Kobler, 2010). It is important that parents do not feel forgotten after discharge. Follow from the hospital. Long-term follow-up with well-timed cards, letters, and phone calls can help families know someone cares. Grief recovery or support groups assist families in finding support from others who have experienced similar loss.

Table 2: Legacy-Making Activities for Families Experiencing Neonatal Loss

- Photographs, including digital and/or professional photography
- Embossed or inked hand and foot prints of the infant
- 2D or 3D plaster molds of infants' hands or feet; can include the parents' fingers
- Artwork, including having siblings make feet/hand prints of infant with their prints
- Scrapbooking; sibling also can make scrapbooks
- Poetry and/or song writing commemorating an infant's life
- Stuffed animals such as a lamb
- Measuring tape used at birth
- Locks of hair
- Special handmade outfits for the infant
- Hand-knit blankets
- Rituals such as blessings, baptisms, naming ceremony, the final bath
- Videotape or photographs of rituals
- Hand-calligraphies "Certificates of Life" that record facts about the infant
- Journaling the experience in a special journal provided by the hospital
- "Memory boxes" to hold precious items

Web Resources

- *Resolve Through Sharing*—http://www.gundersenhealth.org resolve-through-sharing
- *Share Your Story*—http://share.marchofdimes.org
- MISS Foundation—http://www.missfoundation.org
- MEND—http://www.mend.org

Several organizations offer avenues for families to share and make meaning of the loss of their infant. March of Dimes offers an online community called *Share Your Story,* where parents can relay their journey and hear others' stories (Web Resources). Over 30 years ago, Gundersen Health System in La Crosse, Wisconsin, began the *Resolve Through Sharing* bereavement program to educate healthcare providers on how to support families in the death of a loved one. Since then, over 35,000 healthcare professionals have been trained in a "relationship and evidence-based interprofessional approach to bereavement care and education" (Gundersen Health System, 2014). *Resolve Through Sharing* offers conferences, online education, and onsite bereavement training for perinatal, pediatric, and adult death, along with products such as memory boxes, journals, and other items for legacy-making activities with families. Gundersen publishes white papers and books focusing on the importance of relationship, reflection, ritual, suffering, and hope in the presence of death and loss. The MISS Foundation and Mommies Enduring Neonatal Loss (MEND) are organizations specifically created for families after the death of a child.

A hospital's ability to provide effective and compassionate care for grieving families requires a committed program and effort. Nurses should receive education on counseling and supporting families, and even Clinical Pastoral Education where possible (Rosenbaum et al., 2011). Patient care ratios should allow additional care time when assigned to these special patients. Careful cultural and spiritual assessment must be performed to make sure family needs and desires are met. Hospitals should have a strong family support program with knowledgeable and caring staff to provide comprehensive care. Supplies and resources for memory boxes, rituals, making hand and foot prints or molds, and other legacy-making activities should be available. Spiritual care directors or chaplains should be available 24/7, along with a chapel or sacred space for families who wish to be in a special place. Families should receive immediate and longer-term follow-up once they leave the hospital.

A strong, compassionate, and educated support system composed of the healthcare team, extended family, friends, and clergy can have a dramatic effect on how families cope with and find meaning in the loss of their child. Christian nurses' strong commitment to Christ and a faithful prayer life can be lifegiving in sustaining these families. By supporting the knowledge that God is present and wants to provide hope, nurses offer critical care to families experiencing the death of their newborn.

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