

Vision

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Perinatal Care: When life begins and life may end

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Fragility is part of the miracle of birth

By David Lichter
Executive Director

The articles for this *Vision* issue are profound and touching. When we are reflecting on unborn, newborn, or very young babies, we are moved with awe and aware of the tender and fragile nature of our human existence. A good friend in our parish, an OB/GYN, shared with us her perspective on her work, which she views as a ministry. Given all that she knows can go wrong in the complexities of pregnancy and giving birth, she marvels at the miracle of every pregnancy and birth. She is in awe when a baby is healthy; and is compassionate, understanding, and ready to help when it is not. It's part of her spirituality, rejoicing in the "all went well" and being ready for the opposite. She does not fear life's fragility; she expects and embraces it.

It was Christmas Day, 1985, in our family's living room when I probably first faced this experience. My dad had been through a round of radiation for his lung cancer. Still very weak, he was about to decide not to accept any more treatments, and instead choose to embrace hospice. My sister-in-law and brother were present as well. She had just learned the day before that her unborn child, short weeks away from birth, had died in her womb. They chose to wait until the day after Christmas to have her delivered. They named her Mary. The family was gathered first for a home Mass, then presents and dinner.

The room was quiet and still as I began Mass. I was so aware of the painful irony of marking the birth of Christ in our living room with Mary and Dad – one dead and the other dying. We were to be celebrating a birth, the promise and joy of new life, while acknowledging death and the waning of life. While we felt the heaviness and heartache of life, we still went through the ritual motions of Mass, honoring the belief of Christ came among us in our darkness and pain. The shadow of the Cross hung over the manger scene on our small table near the window. The hunched postures of the shepherds and kings now communicated the emotions of heavy hearts, as well as homage.

Yet, we gathered and went through the motions and emotions of the Mass ritual, hoping (praying) that the meaning of take, bless, break, and give would somehow provide a divine context for the human grief, numbness, and blank stares that accompanied the sudden news of death and the gnawing knowledge of dying. We recited prayers, ate the bread, and sipped the wine, believing the news of Christ's birth years ago and his presence with us now.

The next day my brother and sister-in-law had their own private day of birthing and honoring Mary, who was now with the Lord, but who remains present to them to this day, as she is named in every family occasion and marked as family. That Christmas Day she was with us also.

The theme of this issue probably evokes personal memories in all of us. It challenges our feeble faith and strong desire for life. I think chaplains, like my OB/GYN friend, also live in awe of "all went well" but are ready for the opposite. We are with others in those moments, and they need us to ritualize a belief that seems so distant, and as fragile as the one they love.

Ministry after miscarriage supports women and partners

By Jennifer Potter

Many wonderful events happen at a hospital that cares for women and babies, but we also regularly experience tragedy.

My hospital cared for nearly 400 women who miscarried last fiscal year, and 300 the previous fiscal year. I have met with over 500 of those women in the last two years. The patient might have just learned that she is miscarrying and still be in shock. She might be several weeks into her miscarriage and on site for surgical intervention. (The state of Pennsylvania defines a miscarriage as a pregnancy loss up to the 16th week of gestation.) Our goal is to have a chaplain see each miscarrying patient on site to provide initial care and anticipatory guidance for bereavement. I then do a follow-up phone call one to two weeks after she has come through our facility. When needed, I will follow up again one to three months later, if there is a history of depression, a compromised support system, or a lack of coping skills.

I began my work as a chaplain with some good evidence-based training. We use Resolve Through Sharing¹ for bereavement education, a two-day training for care providers. Through that training, I learned an important statistic: 75% of women experience miscarriage as a loss of a baby, and 25% experience it as a medical event. Three-fourths are grieving a life that they have begun to envision. Plans were already well under way. In the remaining one-fourth, the pregnancy ended before attachment occurred. This does not mean an absence of dreams, plans, hurt or grief. It does mean that the grief is different and will need to be addressed differently. For example, to use baby language with our patients who view the miscarriage as a medical event might be confusing. To not use baby language with those who are grieving the death of their child would be offensive.

One of my first tasks is to listen and assess how the miscarriage is being felt. I pay attention to the language used by the patient and her partner, “baby” being the most obvious. I ask how she is making sense of the miscarriage. I try to learn who or what helps her through a difficult time. What are the needs and how might they be addressed on a spiritual level?

Grief can be significant, and while it is individualized, there are several ways to support people. The four areas I regularly explore with patients who have miscarried are:

- Core beliefs that are being challenged by the miscarriage
- Coping strategies
- Support system
- Self-care

Each of these is fertile ground for providing spiritual care. And they are all part of the healing process. Some people comfortably navigate these topics, and our time together is spent identifying the resources already in place. For others, each step is a difficult one. Coping skills and support may be lacking. Self-care may be nearly non-existent. In these cases, I assess and help identify one area to focus on and strategize with my patient about how to meet that need.

In early pregnancy loss, the patient often has a greater attachment to the pregnancy than her spouse or partner does. While the patient is openly grieving, the partner might be sitting next to her looking a bit shell-shocked. Some men confess to feeling confused by the grief their partner is experiencing. Or they feel grief, but less intensely so. Sometimes a miscarriage is the most challenging situation a couple has had to face together so far. I engage both patient and partner to assess how they are navigating the miscarriage as a couple. I normalize the differences they may be experiencing. I encourage ongoing communication and I look for areas in which they might connect. The goal is to invite each person to engage in that shared space, to hear and be heard. Spiritual care is so often about making the invitation to engage another, and stay present for what happens next.

Miscarriage can be physically traumatic, lasting for weeks in some cases. Patients tell me that each day of bleeding is another reminder of the loss. Some patients pass an embryo that is recognizable, which might happen at home with very little warning. Caring for these patients requires an understanding of her full miscarriage experience when she is willing to share it. Helpful questions include, “When did you first learn of your miscarriage?” “What has the experience been like for you?” “What were some of the more difficult aspects of this journey?” Listen to her experience and look for ways to support her and her partner.

I believe one of the most impactful ways we can provide spiritual care is to normalize the presence of grief. Only once have I met someone whose grief exceeded what is to be expected. That patient had a history of depression, was hospitalized with suicidal ideation two months after her first miscarriage, and was now suffering another miscarriage. She clearly needed mental health counseling. While I believe all can benefit from therapy, most of us can work through the grief and loss we experience. We just need the time and space to do so, with some tools to help. Chaplains are able to provide companionship and reassurance. The spiritual care we provide can make a big difference in a person’s ability to grieve and heal. Loss felt in miscarriage can be challenging because of the wide range in which it is experienced. Normalizing the experience may be a huge gift.

Jennifer Potter is a staff chaplain at Penn Medicine General Health’s Women and Babies Hospital in Lancaster, PA.

¹ www.gundersenhealth.org/resolve-through-sharing

Hospital staff can alleviate NICU parents' stress

By Louise Eggen

A mother has had such a good pregnancy and is at a doctor's office for a routine visit. The nurse takes her blood pressure, and next thing you know, mother is told she will be delivering her baby today, even though she is weeks early. Mother has preeclampsia.

Mom has tried to get pregnant and been unsuccessful, so she decides to see a specialist and have fertility treatments. This process is emotionally as well as physically draining, but worth it to have this cherished baby. But then mom and learns that her baby has a fetal anomaly and will need closer observation and likely an ICU stay and maybe even surgery shortly after birth.

A baby is born, and parents are so excited! Suddenly the room fills with staff and baby is whisked to a side isolette because she isn't breathing; staff works on her and the parents briefly see her as she is being sent to the NICU. Dad leaves to accompany the baby.

Baby has been in the NICU for five months, and no one is even mentioning a discharge date. The parents have become familiar with the sounds of alarms, ventilators, IV beeps, etc. They drive to the hospital to spend time with their son and just can't make themselves turn in to the parking structure. They drive past, and it takes an hour before they can come to visit.

Dad has heard so much about his son and been given so many updates by nurses, neonatologists, nurse practitioners, and specialists that he can hardly keep it all straight. Everyone has a slightly different way of speaking of what the baby has encountered and of upcoming procedures. It is difficult to discern whether or not his baby is actually making progress.

Having a child in the NICU is a traumatic event, and parents may have difficulty in adjusting. It is not what they considered when making their birth plan; few even factor into their plan the reality that their baby may be born early or sick or have serious health issues. Few think their baby won't be in the room with mom after delivery. Some families who experience these traumatic events have temporary difficulty in coping. But with time and good self-care, most of them will be able to manage.

As chaplains, we help parents process their feelings, thoughts, worries and concerns about their child in the NICU. We hear about their struggles to manage each day; they can't afford to look at the big picture. Sometimes they are afraid to even decorate their child's nursery at home because the child may not come home.

We know that parents have few places to voice these concerns and fears without judgment and with understanding. We need to touch base regularly with parents and ask about how they are doing. We need to encourage them to speak about their baby. They often need our affirmations that their child is growing or gaining weight or looking cute in this new outfit. Parents want to be parents and brag about their child. Sometimes they need space where they don't have to

hear about the issues with their child but just be a parent who can brag, and chaplains can provide these opportunities.

Mercy Hospital-St. Louis has a Neonatal Intensive Care Unit Parent (NICUP) group, run by parents who had a child who spent time in the NICU and want to give back. NICUPs provide an evening meal or breakfast several times a month to encourage current families to get acquainted. While sharing a meal, parents are encouraged to introduce themselves and share their baby's story. NICUPs facilitate and encourage this sharing by speaking of their own child's journey. They have a common bond and understand what current parents are saying and experiencing. This is another opportunity for parents to begin feeling hopeful as they hear survival stories and hear how children are thriving years later.

Even when families profess to have no connection to a church, they often claim a spirituality. They see a chaplain and think of us as representing God or a higher power. They may find comfort in our praying with them or offering sacraments. We can help them explore their sources of support and then encourage them to reach out. We work with them to name their strengths and needs.

We are not qualified to diagnose, but we can be good listeners and offer suggestions. We can refer them to other programs at our various hospitals that help parents deal with their stress in the NICU. We can hear parents' fears and concerns and speak with a medical staffer and ask them to clarify misconceptions. If our relationships with parents are strong, they may even be open to hearing our suggestion that they consider counseling.

Chaplains provide valuable support and presence for families in the neonatal intensive care unit. We acknowledge what a powerful experience it is to have a baby in NICU and work to affirm and support parents throughout their journey.

Louise Eggen, BCC, is a pediatric chaplain at Mercy Hospital in St. Louis.

NICU parents grieve for their lost expectations

By Christy Medina

The neonatal intensive care unit seems calm and somewhat peaceful. The lights are low and the noise is minimal, with occasional beeping from the monitors.

To me, the NICU feels like a smooth ocean with a rip tide at the bottom. Each patient's family is dealing with their own stress, fear, and grief. The most common story I hear is that the parents did not plan to for their baby to be in NICU, and yet they are now coping with long extended hospitalization. They had everything ready at home — the room, the crib, the baby clothes, extended family visiting, the baby shower, and now this. One mother became teary and emotional as she shared that the only thing she wanted to do was to bring her baby outside to feel the sun. She talked about other family members and friends having babies and bringing them home. "When can I experience the same thing and start my family?" she asked tearfully.

"Your family has already started," I said. "It just looks different for now." I affirmed her gifts as a mother, reminding her of her faithfulness and devotion to be with her baby every single day, even when her own body was healing from giving birth. The baby was in NICU for five months, and at times, the father told me he felt defeated and helpless. I accompanied these parents during their baby's hospitalization, providing them with prayers, friendship, hospitality and silent presence when needed. I even baptized their baby upon admission, due to its critical diagnosis.

Like many parents, they grieved for "the what should have been, and the could have been." The new life that they have dreamt of is now fighting for his or her life. But however it happens, the parents find strength and courage to fight along with their baby. And the calmness of the water is once again restored.

Christy Medina is a NICU chaplain at Children's Healthcare of Atlanta at Scottish Rite.

With love and openness, infant's death won't traumatize siblings

By Tammy Ruiz Ziegler

At the beginning of my time in perinatal palliative care, I was introduced to a couple whose son became my first patient. "Does he have a name?" I asked.

They looked knowingly at each other before answering, "Paul." They later told me that no professional had asked the baby's name since he had received his grave diagnosis.

I encouraged Paul's parents to bring their kids to the hospital so they could share the baby's short and precious life. He was born alive near term, suffering from complex congenital anomalies which caused him to die within an hour. It happened in the middle of the night, and his five siblings, ages 2 to 15, arrived later. But siblings holding a baby who just died is not at all foreign in the world of perinatal palliative care. Each child held him, and I took their picture.

They loved the photos so much, I had to print five copies of their favorite and write each sibling's name on it. They loved, they grieved, they mourned, they survived and later they thrived. They are adults now, and their parents later opened a home for women in crisis and care for moms and babies. And they taught me important things about helping siblings on a grief journey like this one.

In the subsequent 14 years, I have cared for about 70 families who were on a palliative care path. My previous experience as a nurse in pediatric ICU, neonatal ICU, and adult care including hospice, plus CPE training, led me to my current work as a perinatal bereavement coordinator, caring for women and families experiencing miscarriage, stillbirth, and neonatal death.

When I first speak with a mother, one of their first questions is, "Will this traumatize my other children?" The answer is no, and as their chaplain, you can help ensure that this is true.

Very often at my first meeting, the parents have not yet told their other children that the unborn baby is sick and not expected to survive. They often express a deep fear and sorrow that the death of the baby will create an unhealable grief and despair in their children and a confusion about God. It may be the first time these parents have known ahead of time that their children will grieve, and it often sparks a sense of failure and inadequacy. They expected to teach their child about death through pets or elderly relatives, not their child's baby sibling.

I start with creating a safe place where I ask them what they are thinking and feeling. I remind them that children are very concrete and do better with the word "death" than metaphors that will confuse them. I especially caution against the word "loss," because children are terrified of being lost and it sounds like their sibling was absentmindedly misplaced. I share that children often become scared for the mother's well-being and will need reassurance (if it is true) that Mom is not in danger. I remind parents that no matter how the conversation goes, at some point the answer is "we don't know," and there is no shame in that. I encourage them to be honest so that the kids understand the sadness that has overtaken their parents. "Every day

you pour love into your children,” I say. “Please don’t deprive them of a chance to pour some back towards you.”

I worked with a mother who was just terrified that her two- and four-year-old sons would suffer greatly when their sister, Robin, died. The mom later told me the most helpful thing I said was that her sons would know how much they are loved by how she and her husband bore witness to their love for Robin – that if they had been the sick one, this is how they would have been cared for. Her sons met their sister in the recovery room after a C-section and shared some precious moments. Years later, when the younger son was 13, he wrote in a school paper how moving it was, how precious his sister’s life was, and how he respects and appreciates his parents for how they relied on their faith to guide them through such a hard experience.

When children are not included and can tell that something significant is happening, they may feel disrespected and disenfranchised in their own families. However, one recent family chose not tell the children until the birth — but on that day they did so with honesty and clarity, and their children did fine. That reminded me that parents know their children better than I do, and I have come to trust parents.

It has become standard in most hospitals to make mementos of babies who die, and sometimes siblings assist me. A two-year-old can knead modeling compound to make a foot impression and tell me years later that they remember it. I have been known to buy stickers of the siblings’ favorite things that they can stick on the casket, because in their world, putting stickers on something means it is yours. (Father Riley never knew the frog stickers were my idea.)

Infant death is very hard to witness. It is fine to cry and to feel deep compassion. Along with tender compassion, though, I treat parents and siblings as intelligent and capable people who will survive this profound difficulty. I believe they sense my unspoken faith in them, and it helps. My city is small, and I run into these families all the time. There is a certain sweet smile I get from the kids who I met in the course of walking them through the death of their baby sibling. I know they appreciate that they were treated with deference and respect, even if they were very little. I hope you get those smiles one day.

Tammy Ruiz Ziegler, RN, is a perinatal bereavement coordinator at a hospital in Virginia.

Emergency baptisms and blessings range across faiths and cultures

By Glenda Spearman

After nearly 20 years as a Catholic chaplain in a non-religiously affiliated pediatric hospital, I am no longer surprised by the wide variety of calls I receive from the medical staff or families of critically ill patients: “When all else fails medically, call the chaplain!” I may get called to perform a baptism, or to offer a final blessing or prayers at end of life or prior to an emergency procedure. Here are four cases I attended that illustrate the range of needs we see.

Recently, I was called to the bedside of a new arrival to the NICU, **Baby Ellie**, who had been born at a nearby Chicago hospital. Baby Ellie was limp, non-responsive, and “bluish” upon delivery, but the medical team worked until they got a pulse. She was then rushed to our pediatric hospital for further management. After 72 hours, it was determined that Ellie had not taken one breath on her own, had not made any movements of her own and had no brain function.

As the NICU chaplain, I had spent the first two days providing emotional and spiritual support to the tearful father. On the third day, the nurse called me upon the arrival of the mother, who was not only meeting Baby Ellie for the first time but also facing the devastating medical updates that her newborn was at end-of-life. Mother welcomed my presence and asked for prayers, stating she was “a believing Christian” (identified as a non-denominational Protestant). The parents then made the most difficult decision “to let baby Ellie go to keep her from suffering.” I asked the mother, in addition to a final blessing and prayers, whether baptism for Baby Ellie would be of value in their particular Christian tradition. The mother looked up, surprised, and wiped tears from her eyes. “You mean I can get her baptized here? I never even thought about that! That would be wonderful!” On Ellie’s last day of life – when there were no more medical options – she was in a beautiful white satin gown, held by her mother, surrounded by family and loved ones, and baptized by this Catholic chaplain before all the medical tubing and mechanical ventilation and support were finally removed.

Baby Jason was the firstborn child of teen parents. The parents stated that they “believed in a God but not religion” and were “spiritual” but did not go to any church. The teen father declared that he was “a seeker of truth” and was looking into Islam. The mother later confided to me that she was raised “Christian.” In addition to being born extremely premature, Baby Jason had multiple anomalies, and a severe diaphragmatic hernia. Despite their son having a poor prognosis, the young parents had insisted that the NICU doctors “do everything to save our baby.”

Two days after Baby Jason had been admitted to our NICU, the attending physician called me. “Can you come right away?! We have done everything medically for Jason, but his heart rate is dropping rapidly, and we are about to lose him!” When I arrived, the parents and a couple of family members were huddled together in the corner of the room crying, as the large medical team desperately worked on Jason. In the midst of everything, the grandmother of the father spoke firmly to her grandson: “Now I know you both have the final say about Baby Jason. And I know you are thinking about becoming a Muslim. But I raised you to be a good Christian. And while Chaplain Glenda is here and before anything happens, I want this baby dedicated to God, to Jesus Christ!”

The tearful mother nodded; the tearful father just shrugged and replied, “If you want to.” For clarification, I asked the grandmother and parents if they wanted a blessing or a baptism. They all agreed to a baptism. Baby Jason stabilized just long enough for me to baptize him with the parents and even the NICU medical team participating. As if on cue, he quickly declined afterward and died cradled in the arms of his parents. Each parent, the father’s grandmother, and three other family members asked for a copy of the baptismal certificate.

Maggie, a previously healthy and active seven-year-old girl, had been diagnosed with heart damage after a prolonged severe illness, requiring a heart transplant. Her father professed to be Jewish, and her mother grew up Catholic, but neither parent practiced any religion. The father was adamant that he wanted nothing to do with any chaplain or spiritual care services. But after Maggie had been hospitalized for several months, and listed on the heart transplant list, the mother approached me and other chaplains, requesting us to sneak in and baptize Maggie when the father was not around, without ever letting him know about it. We all declined that request.

That all changed one morning when I received an urgent call from Alice, the cardiac social worker. A heart had been identified for Maggie, had been accepted by our doctors, and Maggie was being taken down to surgery now! Alice said that before they left the room, the mother had requested Maggie to be baptized before the transplant surgery, and the father had consented.

I rushed to the cardiac unit just in time to meet Maggie and at least 20 members of the medical transplant team. The entourage stopped in unison when I approached them – they all understood why I was there. “What do you need, Chaplain?” one of the masked nurses asked. “Sterile water,” I replied. Someone handed me a quart-size bottle. I blessed it, reached through to Maggie, amidst the wires, intravenous poles, machinery, and medical team, baptized her, and loudly pronounced “Amen!” The medical team responded “Amen!” and whisked Maggie away to a successful, life-saving heart transplant surgery.

The nurse paged me to the bedside of **Arjun**, an actively dying ten-year-old male cardiac patient. The soft-spoken parents explained that their only child did not have long to live. He had been born with a rare heart disease, and the parents had brought him from India to our pediatric hospital as the last hope for a cure. But all medical interventions had been exhausted, and there was nothing left to do but to keep Arjun comfortable and let him die peacefully. The parents, who were Hindu, had requested the chaplain to say a final blessing over their dying child. I explained that I did not know any Hindu prayers. “But aren’t you the one to represent God in this hospital?” they asked. When I stammered ‘yes’, they insisted: “Please say a beautiful prayer as if Arjun were your own child, so that he would have a safe and peaceful journey.”

To this day, some 19 years later, only God knows what I prayed that evening. But I felt a deep presence of God, who took over my words. Afterwards, the parents looked up with tears streaming from their eyes, nodded, smiled and whispered, “That was beautiful. Thank you!” Arjun died peacefully that same night, but I left their room awestruck, and recognized that something holy had taken place.

Glenda R. Spearman, BCC, is a senior staff chaplain at Ann & Robert H. Lurie Children’s Hospital of Chicago.

Perinatal care raises cultural and ethical issues

By Rev. Chidiebere Evaristus Ogbuagu

A few years ago, I was called to visit a young lady facing a difficult decision for herself and her baby. Because her water had broken and she was bleeding severely, she had to decide whether to terminate her baby — or retain it and most probably die with it. The medical team told her, “Though your baby made it into the 24th week, she nevertheless has very little chance to survive, given your complications. If you succeed in giving birth to her, she may be born with very challenging disorders. If you choose to abort her, you will have the chance to live.” She had long waited patiently and sacrificed a lot to conceive her first child. She was totally broken, and the emotional trauma that followed was unfathomable. Her husband and sister were pacing up and down the maternity hallway, waiting to hear from the care team. As soon as the care team came out of the room, they rushed them with questions: “Is she okay?” “What next?” “What of the baby?” “What shall we do?” “Can we help?”

As a chaplain, I noticed that words would not bring any immediate solution. The sustained ministry of presence was relevant. I stayed with the expectant mother and her family until she made the decision to let go the child in order to save her own life. It was a very sad situation. Preeclampsia (the situation which she was suffering from) and other complications before and after birth radically change the subject of childbirth from joy and hope to fear and sorrow.

Cultures and religions across the world speak to the ethical obligation of life preservation. Tenaciously, many of these cultures hold life as sacred and are obliged to integrally preserve and promote it. It all begins with the health and wellbeing of the mother and extends down to the baby to be born.

Across cultures, children are viewed as gifts from God. Innocence, purity and sacredness are often ascribed to the unborn, the newborn and children. In their vulnerability, the society strives to protect and defend them and to assist the mother through pregnancy and delivery. Most cultures believe that children’s souls return to God immediately after death. But of course, most parents who lose their children at such tender age, including miscarriage, feel great emotional trauma and pain. Parents struggle to come to terms with the devastation of the loss and often get less support from society than they would for the death of an older person. This, sometimes, tends to place prenatal loss in the category of disenfranchised grief or “silent loss.”

In the ethical realm, perinatal care can be complex. The case I described above took place at a Catholic hospital, and we faced the question of whether it was ethically permissible to permit the termination of the fetus if allowing the child to be born would lead to the demise the mother. Both the mother and her child were in imminent danger of death. The USCCB’s Ethical and Religious Directives¹ 45 through 47 regulate this kind of situation. Number 45 specifically states: “Abortion (that is, the directly intended termination of pregnancy before viability or the directly intended destruction of a viable fetus) is never permitted. Every procedure whose sole immediate effect is the termination of pregnancy before viability is an abortion, which, in its moral context, includes the interval between conception and implantation of the embryo.

Catholic health care institutions are not to provide abortion services, even based upon material cooperation.”

However, in the above case, it was obvious that both the life of the mother and her unborn were in danger and could be lost. The only solution available appeared to be aborting the baby — but it was not for the intent of termination. ERD 47 stipulates: “Operations, treatments, and medications that have as their direct purpose the cure of a proportionately serious pathological condition of a pregnant woman are permitted when they cannot be safely postponed until the unborn child is viable, even if they will result in the death of the unborn child.”

In perinatal loss, when the bereaved parents are feeling distraught and alone at time that was supposed to be full of happiness, chaplains facilitate the family mourning process and help them begin their journey of recovery. Through ministry of presence, open-ended therapeutic communication, active listening, compassionate and non-judgmental sensitivity and respect for diverse cultural and religious beliefs, chaplains provide comfort, solace and support. We can make a difference for the parents, their family members and the entire community. In such solemn, challenging moments of loss, chaplains step in to empathize and provide spiritual and emotional strength.

Rev. Chidiebere Evaristus Ogbuagu is a chaplain at Mercy Health-St. Elizabeth Hospital in Youngstown, OH.

¹ <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>

Regular perinatal burial service honors families' loss

By Jan McDonnell

The program to support families experiencing perinatal loss at Ascension Saint Agnes Healthcare goes back many decades, and has changed over the years. But after the immediate counseling in the wake of loss, we offer free burial for all babies who expire in the perinatal period.

We provide burial for every loss, from very early miscarriage through full term. An early miscarriage may generate a specimen that is processed through surgical pathology, including material that women bring in to our ER from losses experienced at home. We also include surgical specimens from ectopic pregnancies. If a woman with an ectopic pregnancy is admitted, the chaplain will offer support as for any other pregnancy loss.

Babies' remains are stored in a special location in the hospital morgue. We encourage families who are interested to explore private burial, but very few make private arrangements because of the cost. Surgical specimens are automatically kept and stored.

Our infant burial service is held twice per year. The Daughters of Charity donated a plot they held at a local Catholic cemetery, and arranged for a headstone. Nursing, registration and pathology developed a protocol for arranging for burial permission, with policies and procedures approved by Mission Integration and the board of the hospital. New Cathedral Cemetery provides tents, chairs, site preparation, and help during the service. A local funeral home donates a casket, transport, storage, and help at the service. Mission Integration budgets and arranges for flowers.

Spiritual Care sends invitations to families whose babies will be included in the ceremony. We take care that the interval between the baby's death and the service is no less than four weeks. The interval lets mothers recover from delivery and gives families time to support each other privately during those first few weeks of intense initial grief.

We also take care to be both reverent and lawful as we prepare to bury the bodies of these precious babies. Registration and Nursing obtain permission to bury from parents, assemble death certificates as appropriate, and collect state forms. Two days before the service, the funeral home brings the casket to the morgue. After a prayer by the chaplain, the babies' bodies are placed in a single casket (or two, if needed) by the pathologist, as the nurse-manager, chaplain and funeral director make sure the paperwork is in order. The funeral home stores the casket until the service, and brings it to the grave site along with stand, podium, tissues, water, and other supplies.

On the day of the service, we give out flowers, pins and programs at check-in, when we also note each baby's name. Nurses and others who have been involved in care of mother and baby, Daughters of Charity, and others from Saint Agnes attend and welcome the families.

The programs, in English or Spanish, include prayers that we recite together, including Psalm 23. Portions of the service are conducted in both languages by a chaplain who speaks Spanish. Our service is brief, only 15 minutes long, and includes reading of all the babies' names. Babies who have not been given formal names are named aloud as Baby [mother's last name]. The burial service itself is Christian, and includes a reading from the Gospel. But families of other faiths are invited to conduct their own private prayers and rituals afterward if they wish. The chaplain remains for those prayers as well, as do many of the other families. The universality of the grief at the death of a child is a strong bond among those of every faith.

Between 30 and 75 people attend, depending on the number of babies included. Every time we have a service, we find new toys, stuffed animals, angels, plants, and flowers placed on or near the stone. Trucks, action figures, dolls, teddy bears, balls, rattles, painted rocks, Rosaries — the babies touch many hearts and inspire gestures of love.

Once in a while, a woman who has experienced a loss years earlier calls Spiritual Care to ask about our infant burial program. They are hurting because they do not know what happened to their baby's body, or because they know that it was treated as medical waste. We send these women an invitation to the next service, and promise to speak the name of their child along with all the other names, if they wish. We make sure they know where the site is, and encourage them to make it their own even if they do not come to a service.

For families to whom the burial matters, it matters very much. When we demonstrate love and reverence for each baby, our grief at the death of each child, and our care and concern for each family member — when we hold a ritual and give them a place that acknowledges their loss — when we affirm God's love for each child and each one who grieves — then we are providing an opportunity for healing grace that is a gift from God to all, transcending language, culture, race, religion, role, and more.

As the Ascension mission statement says, continuing the loving ministry of Jesus as healer, we commit ourselves to serving all persons, with special attention to those most in need. Amen.

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Spiritual care in the perinatal space: Evidence from research

By Austine Duru

Perinatal care is fraught with complicated emotions and challenging dynamics. Issues may come up during the pre-term labor and delivery, or in the neonatal intensive care unit. Sometimes families may face the unthinkable loss of a baby before, during or after labor. In each of these situations, chaplains play a crucial role in supporting the complex needs associated with perinatal care. There is substantive research literature that provides insights and helpful strategies for effective spiritual and emotional support for patients and families in chaplains' care.

Nurses are often closest to patients and families and are consistently able to correctly identify their needs. In perinatal care the nurses play a crucial supportive role at a very emotionally turbulent time. This becomes a bit tricky when the needs are not clearly clinical, but deeper existential and spiritual needs. In a 2017 study, "Perinatal Loss Chaplain Utilization: What Nurses request and what Patients Actually Need"¹, Melanie L. Chichester and Sheryl Allston explore how frequently nurses accurately assessed the spiritual needs of patients and families in perinatal loss, and they compared this to the spiritual care assessment completed by chaplains for the same patients. The results suggest that while nurses did include the chaplain most of the time, they did not consistently accurately identify the family's needs for emotional or spiritual support. A more telling finding is that nurses underestimated their own need for support in the midst of care. The findings suggest that chaplains have an opportunity to educate nurses and other clinicians about the spiritual needs of perinatal patients and their families, as well as help address the needs of the caregivers.

Cultural sensitivity and humility are crucial in perinatal care. Three recent articles explore this subject from Muslim, Latino, and African-American cultural perspectives. In "Perinatal Grief in Latino Parents"², C. Whitaker, K. Kavanaugh, and C. Klima (2010) explore the literature surrounding perinatal grief and loss in Latino culture. In a similar literature survey, "Experiences of African-American parents following perinatal or pediatric death: A Literature review"³ J. Boyden, K. Kavanaugh, L.M. Issel, K. Eldeirawi, and K. Meert explore the unique factors that impact African-American perinatal bereavement. "Psychosocial impact of perinatal loss among Muslim women"⁴ speaks to the importance of attending to the family as a unit in addressing perinatal grief for Muslim patients.

Estimates of stillbirths in the United States suggest that about 25,000 stillbirths occur each year, or about 70 each day (M.C. Kelley and S.B. Trinidad, 2012). The growing research and focus on perinatal loss often does not account for lived experiences of patients and families. "Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth – a qualitative study"⁵ attempts to address the praxis of experiencing stillbirth and the challenges of the stigma and taboo that surround it. The authors highlight the importance of creating conducive environments to address the needs of women and families experiencing a stillbirth, as well as attending to the emotional, physical, spiritual, and cultural needs of patients. The importance

of recreating memory for these patients raises important questions about the use of rituals in their care. Chaplains could be key partners for clinicians here.

It is often said that a picture is worth a thousand words. This is symbolically and literally true when dealing with perinatal loss, whether it is a fetus, stillbirth or an infant. Words often fail to convey the depth of loss and devastation felt by parents and families. In a very recent study, “Professional bereavement photography in the setting of perinatal loss: A qualitative analysis”⁶ F.D. Ramirez, J.F. Bogetz, M. Kufeld, and L.M. Yee (2019) investigate the role of professional bereavement photography in perinatal loss and grief. They also explore the perspectives of bereaved parents, professional photographers, and interdisciplinary healthcare teams. The final analysis identified five major themes that suggest bereavement photography does add value to parents. These include, “validation of experience, permission to share, creation of a permanent and tangible legacy, creation of positive memories, and moving forward after loss.” This seems to become more effective when combined with other grief support initiatives.

The spiritual and theological issues raised by stillbirth for healthcare chaplains⁷ by D. Nuzum, S. Meaney, K. O’Donoghue, and H. Morris (2015) published in the *Journal of Pastoral Care & Counseling* explores the spiritual and theological questions that chaplains wrestle with as they attend the parents who have experienced perinatal loss. The study recognizes the emotional toll of attending to the complex needs of bereaved parents, and aims to understand how ongoing support for families experiencing perinatal loss affects the chaplain’s theological and spiritual attitudes. The findings suggest that encounters with perinatal loss raise serious existential, theological, and spiritual questions for chaplains. The authors identified three main theological themes that surfaced from the study: suffering, doubt, and presence. They recommend self-care and the practice of theological reflection as a tool for coping with perinatal care chaplaincy. A full text of this article is available by logging in to the publication through the resources link in the NACC website⁸.

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¹ <https://sigma.nursingrepository.org/handle/10755/622684>

² <https://www.ncbi.nlm.nih.gov/pubmed/20975393>

³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3994462/>

⁴ <https://www.ncbi.nlm.nih.gov/pubmed/22708998>

⁵ <https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-12-137>

⁶ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6572886/>

⁷ <https://journals.sagepub.com/doi/abs/10.1177/1542305015602714?journalCode=pcca>

⁸ NACC members only. Use the Member Login button on the NACC website.

Spiritual support of pediatric staff takes many forms

By Jim Manzardo

A code has been called, and as doctors and nurses tend to the patient, the family is falling apart in the room. A senior attending launches into a tirade about a resident doctor's care decisions. Office staff are grieving the news that one of their colleagues just died. A medical team is distressed about a family's decision for aggressive care for their infant. A bedside nurse, overcome with sadness by the death of a baby, sits alone in tears. NICU staff feel that a particular space has held one too many traumas and deceased patients and needs a cleansing. A respiratory therapist is stunned by the angry outburst a parent directed at her.

Daily, in addition to direct patient and family care, chaplains respond to staff who are stressed and need support. But our institutions and administrators seek evidence that our chaplaincy is valuable. Anecdotally and from research,¹ we know that chaplains add to the effectiveness of healthcare systems and contribute to patient satisfaction,² but little research has been done on the impact of our support of staff. Anyone needing to do some research?

A recent National Public Radio story³ spoke of why healthcare and education costs rise so much more than anything else. The answer: because their customers expect, want and need the time and presence of those providing a service. But financial pressures and institutional expectations greatly limit the time availability of many who work in healthcare. We chaplains strive to accommodate these *chronos* time pressures while hearing the call of the sacred *kairos* moments when, as Madeleine L'Engle writes, "we are BEing...and are freed from the normal restrictions of time."

We chaplains often must be creative to balance the demands of patient and family care with staff care needs. Some years ago, during the daily morning conference call for all leaders, our manager began announcing overnight patient deaths, the impact those deaths were having on the unit staff, and the supportive staff role the chaplain played. The latter two were a revelation to many leaders and increased their awareness of our role.

My chaplain colleagues and I at our urban pediatric hospital have long been well supported by our institution, demonstrated especially through increased staffing over the years. That support has grown in large part because of our support of staff, both indirectly and directly.

Chaplains indirectly support staff through our care of patients and families. We respond to staff calls and show up in times of crisis. We enter into and hold distressing, traumatic, grief-stricken spaces. We witness and engage those spaces and the people in them. We listen and respond to the breadth of spiritual distress that patients and families often begin to express to staff. We bring a calm, grounding, compassionate presence. We remain as long as we assess our presence is necessary and as long as our time permits. We both empower patients and families to advocate for themselves and serve as their voice and mediator when they cannot.

Through these actions, we free up staff to focus on their tasks. But we also model a quality of care which staff can and do bring to their encounters with patients and families. See this recent study⁵ about how nursing staff provide spiritual care. Yes, we know everyone in healthcare has the opportunity to treat the human spirit.

We also support staff directly in one-on-one and group settings, in planned and spontaneous encounters, in times of personal and institutional crises and in times of celebration. Staff tell us how much they value our informal check-ins and more formal debriefings, especially following very challenging situations, such as a patient or staff death, traumas or codes, and when family members project their stress onto staff. Nearly every time an employee has died, we chaplains have met with the deceased's colleagues, witnessed to and held their grieving, and facilitated reminiscing. As one prone to move quickly through back hallways and, I know, missing kairos moments, I am inspired by a chaplain colleague whom staff seek out *because* she is more attuned to these sacred moments. The more we are available, the more they request our services.

A few years ago, I initiated a weekly chaplain-facilitated 20-minute meditation in our hospital chapel. The mostly behind-the-scenes hospital staff appreciate this restful and rejuvenating pause. Some chaplains have supported staff for many years through our hospital's orientation for new nurses. During their first 18 months, the new nurses meet periodically in small groups, facilitated by a chaplain and experienced nurse, to share their joys and struggles. We bring encouragement as these new, and often young, nurses realize they are not alone, we extend affirmation as they face and overcome their worst fears, and we celebrate their accomplishments. We also affirm the spiritual care *they* provide patients and families, through their empathic listening and compassionate care.

We minister to and support staff whenever we take interest in their lives, their families, their joys and their struggles; in our praying with them and providing them with religious and spiritual resources; in providing them with opportunities in our institutions for nurturing their spiritual life and practicing their rituals such as meditation, Muslim prayer, ashes, Communion.

As we are pressed to prove the value of our time, we must promote the positive impact of our ministry to staff within our places of employment. The more content and well cared for staff feel, the better they can provide their very best care.

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¹ Cunningham CJL, Panda M, Lambert J, Daniel G, DeMars K. *Perceptions of Chaplains' Value and Impact Within Hospital Care Teams*. *J Relig Health*. 2017 Aug; 56(4): 1231-1247.

Flannelly, K., Galek, K., Bucchino, J., Handzo, G. F., & Tannenbaum, H. P. (2005). *Department directors' perceptions of the roles and functions of hospital chaplains: A national survey*. *Hospital Topics*, 83(4), 19–28.

² <https://link.springer.com/article/10.1007%2Fs10943-018-0604-4>

³ <https://www.npr.org/2019/10/04/767095401/the-baumol-effect-and-rising-health-care-and-education-costs>

⁴ <https://www.amazon.com/Walking-Water-Reflections-Faith-Art/dp/0804189277>

⁵ <http://ajcc.aacnjournals.org/content/27/3/212.full.pdf+html>

Authors' idea of 'new happiness' has been around for millennia

Matthew McKay and Jeffrey C. Wood, *The New Happiness: Practices for Spiritual Growth and Living with Intention*. Reveal Press, Oakland, CA, 2019.

By John Gillman

This book's title seems to imply that a novel discovery about happiness has been uncovered. In contrast to the "old" happiness, which the authors define as based on the acquisitions of money and possessions, they argue that "new" happiness stems from values and actions; it is a process, they claim, of "doing" rather than "believing." Coincidentally, I'm writing this on a Sunday when the day's Gospel reading is about the path taken by a rich man to acquire "old happiness." His approach was to build larger barns to store his bountiful harvest, enabling him to spend many years resting, eating, drinking, and being merry (Luke 12:13-21). Readers of this review will probably remember that it didn't turn out well for him.

Stating that they want to avoid the debates about God, spirituality, and religion, these authors — neither of whom belongs to an organized religion — intend to offer a secular guide to spirituality. They steer clear of the wisdom offered by religious traditions until chapter 12, when they draw upon the insight of the Buddha, who taught that suffering arises for those who fail to grasp that all things are impermanent. That weakens their argument for novelty. And to cite the Christian tradition, the teachings of Jesus and the values highlighted by Paul — see for example the "fruits of the Spirit" (Gal 5:22-23) — would suggest that the secret to genuine happiness is not really new at all.

On the positive side, the worksheets included throughout the book may be useful in identifying values (chapter 2), evaluating choices (chapter 3), coping with pain (chapter 4), practicing deep meditation (chapter 5), identifying life purpose (chapter 6), rehearsing values-based actions (chapter 7), gaining wisdom from the Spirit, vaguely defined as entity or source (chapter 8), identifying barriers in living one's spiritual values (chapter 9), being compassionate to self and others (chapter 10), making amends (chapter 11), using the lens of impermanence (chapter 12), finding a "state of grace," viewed "not [as] a gift from God," but something you give yourself (chapter 13), and making a long-term spiritual action plan (chapter 14).

However ... the authors, while maintaining their secular perspective, would have enriched their discussion by dialoguing with what philosophers and teachers (even religious ones) through the ages have learned about the true nature of happiness.

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