



# VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

## Pregnancy Loss





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UNIVERSITY PRESS



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### **No Footprint Too Small**

No Footprint Too Small is a 501c3 nonprofit organization located in Lincoln, Nebraska. Its mission is to provide comprehensive perinatal support to mothers, fathers, and families affected by pregnancy or infant loss. The ways in which No Footprint Too Small supports mothers and families are continually evolving. Some of the services and support No Footprint Too Small provides at little to no cost are:

- Care packages
- Weighted memory bears
- Guidance with burial/funeral arrangements
- Financial assistance for mental health therapy with a licensed provider
- Financial assistance for burial/funeral expenses
- Restorative yoga classes
- Support groups
- Remembrance events

### **Special Thanks**

Thank you to the authors for sharing their stories with us and to the many individuals known and unknown who donated to make this edition of VOICES possible. We dedicate this edition of VOICES to all those affected by pregnancy loss or infant death and in honor of Teddy.

## Introduction

# Pregnancy Loss

Elena Kraus<sup>\*†</sup>

<sup>\*</sup> CHI Health Clinic Maternal Fetal Medicine, St. Elizabeth Hospital and Creighton University Medical Center

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**Conflicts of Interest.** The author reports no conflicts of interest.

**Abstract.** This symposium includes 12 narratives from people who have experienced pregnancy loss at any stage of pregnancy or during labor and delivery. Stories of pregnancy loss are seldom shared, and bereaved parents must navigate their grief, anger, confusion, guilt, shame, or other feelings alone. They may be left wondering, “Did I do something wrong?”, “Will this happen again?” or “How do I grieve this loss?” Other people who experience a fetal death may feel relieved or conflicted by the loss, causing stress on their relationships. Family members, friends, and healthcare professionals may be unsure about how to respond to or support people who have experienced pregnancy loss. These narratives foster a better understanding of the emotions people experiencing pregnancy loss may feel. The authors describe what was helpful and what was lacking in their interactions with healthcare providers and loved ones in the time following a fetal death. This issue also includes 4 expert commentaries written by Tammara Ruiz Ziegler, Kathryn R. Grauerholz, Raymond De Vries, and Elena Kraus.

**Key Words.** Medical Ethics, Narratives, Pregnancy Loss, Miscarriage, Intrauterine Fetal Death (IUFD), Bereavement, Stillbirth

### Introduction

Pregnancy loss is a devastating, yet common experience for women and their families, and no location or demographic group is spared. Early pregnancy loss, defined as loss prior to 12 weeks 6 days gestation, occurs in 10% of clinically recognized pregnancies, but is estimated to occur in up to 25% of all pregnancies (American College of Obstetricians Gynecologists’ Committee on Practice Bulletins—Gynecology, 2018). Among these losses, 50% are due to chromosomal abnormalities, and the majority are not considered to be preventable

(American College of Obstetricians Gynecologists’ Committee on Practice Bulletins—Gynecology, 2018). Stillbirth, defined as a loss at greater than 20 weeks or greater than 350 grams, occurs in 1/160 deliveries (American College of Obstetricians Gynecologists’ Committee on Practice Bulletins—Gynecology, 2009). Risk factors associated with stillbirth in developed countries include race, nulliparity, advanced maternal age, obesity, chronic hypertension, preexisting diabetes, smoking and alcohol use, and the use of assisted reproductive technologies (American College of Obstetricians Gynecologists’

Committee on Practice Bulletins—Gynecology, 2009). Despite its categorization as a poor pregnancy outcome, rates of stillbirth have not significantly changed in the last 20 years, and now surpass rates of infant mortality (Woods, 2008). Although there is a great focus on reducing mortality after birth, fetal mortality garners less attention.

The reasons for this lack of focus are several. Causes of loss are often complex and not well understood, and many healthy women suffer unanticipated and unexplained losses. Even with thorough postmortem examinations, often no clear cause can be identified (ACOG, 2009; Woods, 2008). Furthermore, only some known risk factors are modifiable. Further hindering our ability to address trends in pregnancy loss at all stages, the definitions of early pregnancy loss, abortion, stillbirth, and fetal death are complex and have social and biological constructs that vary across cultures and countries. These inconsistencies hinder accurate recording, comparisons, and, ultimately, understanding the causes to reduce fetal mortality (American College of Obstetricians Gynecologists' Committee on Practice Bulletins—Gynecology, 2018; Woods, 2008).

Although we lack understanding of why and feel somewhat helpless to alter this outcome, we do know how traumatic these events can be for the women that experience them, and the potential lasting effects. Studies have shown pregnancy loss changes future pregnancy planning, relationships, increases depression and anxiety, and changes subsequent parenting behaviors (Lamb, 2002). Even early loss can alter a woman's perception of herself as a woman and mother and, in some cases, affect relationships with future children (Bicking Kinsey, Baptiste-Roberts, Zhu, & Kjerulff, 2014). Healthcare providers are in a unique position to help support parents in processing and healing from pregnancy loss. Unfortunately, their well-meaning attempts at consolation often miss the mark, as it is challenging to truly understand the depths of parents' suffering and how to support them in healing (Kelley & Trinidad, 2012). Ultimately, our medical and social constructs make it difficult for parents to feel heard, express their grief, and receive appropriate support

in healing. For these reasons, it is crucial we create spaces for parents to express their perspectives and to learn from their stories.

## The Call for Stories

In the call for stories, we sought personal narratives from parents who had experienced the loss of a fetus at any stage of pregnancy or during labor and delivery. Early on, we received questions from the public, asking us to clarify if we only wanted stories from people who had living children because of the use of the word *parent* in the call. The editors discussed this question and determined that we considered parents to mean anyone who has ever had children or expected a child. As a result, I use the word *parents* throughout this introduction in that context. We were open to including stories from parents of any gender. We received stories mainly from women, though one submitted story was written by a husband and wife pair. Most of the stories are from authors in the United States, though we also include stories from authors in Switzerland, Lithuania, and Japan.

We invited authors to share their experiences with losing a pregnancy at any stage, including the emotional experience, how it was processed, and the experience of later pregnancies after pregnancy loss. We also asked them to consider how the loss affected their relationships and identity as a parent. We invited them to describe ways they felt support and their experience with their clinicians. We asked for their advice for others going through similar situations, and what types of support helped them grieve. We were interested in learning about any themes related to pregnancy loss as a whole, but also of pregnancy loss in different circumstances and stages, such as at different gestational ages, and anticipated losses related to terminal fetal diagnoses. Several stories were submitted by those who suffered losses in the context of infertility and within the process of assisted reproductive technologies, which added additional breadth to the traditional concept of pregnancy loss.

Authors were asked to consider the following questions:

- Describe your experience with pregnancy loss or of losing your child during labor and delivery. What emotions did you experience? How did you process these emotions? Describe your experience of childbirth after a loss.
- How did your loss affect your relationships with your partner, friends, and family? How did it affect your identity as a parent? How did your friends and family support you, or in what ways was their support lacking?
- How did your clinician respond or support you after the loss of a pregnancy or infant? What, if any, were helpful forms of support for you?
- What would you like clinicians and other healthcare providers to know about your experience? What could they do, if anything, to better support bereaved parents or people who have experienced the loss of a pregnancy or death of a fetus?
- What advice do you have for others experiencing pregnancy loss?
- Describe your experience of later pregnancies and childbirths after pregnancy loss.

The editors of *Narrative Inquiry in Bioethics* published the call for stories in the NIB newsletter and on the NIB Website. Additionally, the call was posted on several social media platforms, including LinkedIn, Facebook, and Twitter. It was distributed through the American Society for Bioethics (ASBH), the Medical College of Wisconsin (MCW), the University of North Carolina (UNC) Center for Health Equity Research, the California Ethics Consortium, and the Saint Louis University listserves. Thank you to Tammy Ruiz, a critical care, perinatal loss, and NICU nurse, for sharing the call within her network—we received several proposals with her help. The editors also shared the call with friends and family and on their personal social media accounts and through a Facebook group for OB/GYN moms.

## The Narratives

Here we share 12 stories from parents who experienced pregnancy loss at many stages of pregnancy. Eight additional stories are available in the online supplement. The story authors describe a range of experiences, from early miscarriage to losing a child during labor and delivery. Some of the authors

experienced a loss after undergoing expensive, time-intensive, and emotionally overwhelming infertility procedures. For most of the authors, the loss was unexpected, though one story is from a mother whose baby was diagnosed with anencephaly while in utero. This mother continued with her pregnancy despite her baby's prognosis and the inevitable outcome. The authors discuss the reactions of health care providers, partners, and family members and some speculate as to what caused the loss. Many offer advice on what actions or resources they found helpful. Others provide recommendations on what not to say to a bereaved parent. Many of the authors describe the process of moving on and healing emotionally from their losses though some talk about the guilt and sadness they feel, even years later.

## The Commentaries

This symposium includes four commentaries. The commentaries draw out themes and lessons learned from the narratives. The commentary authors include experts in obstetrics, reproductive and perinatal loss, palliative care, hospice, fetal loss, bioethics, NICU nursing, and the delivery of maternity care.

Tammara Ruiz Ziegler is a Perinatal Bereavement Coordinator. She is certified in perinatal loss care. Ruiz Ziegler has cared for at least a thousand perinatal loss cases and has published works on perinatal palliative care and fetal loss disposition. She has her MA in bioethics and a Bachelor of Science in nursing.

Kathryn Grauerholz is an Adult Nurse Practitioner and an Advanced Certified Hospice and Palliative Care Nurse. She has over two decades of experience working with adult patients in hospice, antenatal distress counseling, and reproductive loss. Kathryn serves as the Director of Healthcare Programs at the Institute of Reproductive Grief Care. She has presented on the topics of perinatal palliative care and reproductive grief care to healthcare professionals nationally and internationally.

Raymond De Vries is Professor Emeritus in the Department of Obstetrics and Gynecology and the

Center for Bioethics and Social Sciences in Medicine at the University of Michigan, Ann Arbor. Dr. De Vries is a sociologist who studies the organization and delivery of maternity care and the ethical dimensions of that care.

Elena Kraus is a Maternal Fetal Medicine Specialist at CHI Health Clinic in Lincoln, Nebraska. She also has an academic appointment and sees patients at Creighton University Medical Center. In addition to providing high-risk perinatal care, Dr. Kraus has a PhD in Health Care Ethics, and has significant experience in qualitative research in the areas of primary care, medical teamwork, and women's health.

## Conclusion

As a whole, this symposium offered rich and personal descriptions of pregnancy loss as a potentially life-altering event. The stories illustrate the intensity of emotion and deep sorrow that women and their families experience regardless of when the loss occurs, and the significant impact the experience has in the short and long term. These effects are multifaceted and influence these mothers physically, emotionally, and spiritually, with lasting effects on their relationships, family, and subsequent pregnancies and deliveries. The stories clarify the personal nature of pregnancy loss and the stark contrast that exists between the perspectives of those who live it firsthand, and the perspectives of those that care for them during and after loss. Their voices humanize an often medicalized event and contribute significant insight into how community and healthcare providers can best care for parents during this difficult experience.

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## Personal Narratives

### You Can Do Hard Things

Christina Mulé

It was the day of my first ultrasound, which was delayed due to COVID-19. It also happened to be the first day that a support person was allowed to attend prenatal appointments since the pandemic hit. I was so grateful that my husband, John, could be there to share this experience with me. We were eager to meet our baby, who I was convinced was a boy. It was settled. I would be a hockey mom and that was that.

The sonographer placed the ultrasound gel on my abdomen, and I asked John to get ready to record the visit so that we could share the ultrasound with our families. No one in my family, except for my sister, knew about the pregnancy yet. When the sonographer said, "let's just wait a minute to make sure everything is okay," I knew at that moment it wasn't. She confirmed one of my worst fears. Our baby measured at 6 weeks gestational age, the placenta measured at approximately 11 weeks, and there was no heartbeat.



I tried not to cry, or maybe I was too shocked to respond. I had a really great first trimester with no morning sickness and pregnancy symptoms that were uncomfortable but tolerable. I thought I was just “one of the lucky ones.” I had no symptoms of miscarriage, and my body continued to nourish the placenta as if I were truly still pregnant. I single-handedly ate a whole family-sized bucket of animal crackers in about a week! Making it to almost 11 weeks I thought that I had “made it.”

The news finally sank in and I wept on the table, never knowing just how vulnerable I could feel.

My doctor, Dr. P, an Indian woman not quite old enough to be my mother, but with the warmth and maternal bedside manner that I needed, came into my room and discussed the options with me. In an attempt to be prepared for anything, I had already done plenty of research before this day. I knew I wanted a dilation and curettage (D&C) procedure. Frankly, my body believed it was still pregnant, so it was hard to know when natural abortion would have happened. Would it have been several more weeks? I couldn't carry on just waiting.

From there everything became blurry. I was told I was being white sheeted for emergency surgery, which meant that I didn't have an appointment but that I'd be called once there was a time in the operating room (OR) available. I didn't know if it would be tomorrow, the next day, or even later. And depending on when I got the call, it would determine who would do the procedure. My doctor was not on service for the next two days, so it would be Dr. C if I got called during this time period. I was okay with this. Dr. C was my second choice OBGYN. She studied at ivy leagues and completed her residency training at a highly regarded academic medical center. Her resume met my standards. What I heard loud and clear is that I needed to get a COVID-19 test immediately. I signed all the consent documents with tears streaming down my face, Dr. P hugged me, and then we rushed to a COVID-19 clinic so I could have a polymerase chain reaction (PCR) test with “STAT” status.

The rest of the day was blurrier. I worked to communicate as best I could with my own clinic to clear my schedule. With the help of an amazing administrator, my own patients were taken care

of, and I just had to manage the rest. I was able to communicate to everyone that needed to know that I'd be out. Regretfully, I missed a meeting with a very influential colleague whose calendar was very difficult to get on, and I still feel guilty over this. Somehow life kept moving when I just wanted it to stand still.

I spent the night telling my family what was happening. Of course everyone was shocked and tried to be as supportive as they could be from afar. My mom asked if she could come be with me but with the uncertainty of COVID-19, it just didn't make sense. We went to bed and I cried the whole night, but tried to keep it from John who was sad and having a hard time expressing himself. Maybe we both felt like we had to hide our sadness and pain from each other or maybe if we seemed strong we could get the other through? The truth is we were both a mess and we knew it.

We finally got out of bed at 5 am, showered, and waited for a call. I hadn't eaten much since learning the news and I was told to fast for the surgery, but by 7 am, I was starving! My body still believed it was pregnant and it was signaling to eat. We got a text at 9:10 am to pick up medication (misoprostol) that I learned needed to be inserted vaginally 4-6 hours before the procedure to soften the tissue in my uterus but at 9:30 am, we got the call from the hospital that OR time was available. I was so confused and scared. I hadn't even had a chance to pick up the medication!

We stopped at the pharmacy and then John put the hospital address into our GPS. Off we went, but in my own daze, I didn't realize that we were going the wrong way until we approached a lake. John had driven to a satellite office—we were totally in the wrong place! I know what the campus I work on looks like! The stress of it all brought on some bickering. I needed to cut him some slack. It wasn't just me going through this, he was just as much in this as I was.

We finally arrived to the right location and I laid into the nursing staff. Why wasn't I given a procedures list with an exact address of where I needed to go? Why wasn't I told in advance about this medication? Can we move forward with the procedure? I work in the healthcare system myself

and I deliver bad news every day. Didn't they know that the brain's memory center shuts down when people are stressed? I wanted some sense of control and predictability at a time when I felt like I was losing everything.

The staff quickly realized I worked in healthcare and that I was faculty at the university medical center. The damage was done but they did their best to turn it around. They explained that due to the pandemic, John would need to leave when I was transported from pre-op to the OR, but that they were working on a "workaround" to allow him to stay. A nurse-angel, Chris, who had come back to nursing after retirement, figured it out! John was given a new badge and explicit instructions not to wander the hospital floors. I don't know if he was allowed to stay because they felt bad for me, because I was so upset with them, or because it was a courtesy they offered due to my faculty status. Whatever the reason, I was grateful.

I met Dr. C and even though she had the perfect resume, I didn't like her. She had a "put me in, coach" kind of attitude. She was frustrated with me for requesting genetic testing on the fetal tissue, which would slow things down due to additional consent procedures. She explained that it was likely unnecessary and that the cause of miscarriage was probably the result of a chromosomal abnormality. I already knew this, but I needed to have confirmation to move on and let my mind rest. To her this was just another miscarriage and just another procedure, but for me, this was my baby and all of our hopes and dreams. I didn't like her but she was competent and I rolled with it. What choice did I have?

I met with anesthesiology and they started a drip of valium and later propofol. John said goodbye and with tears in his eyes said, "everything's going to be okay." They started transport to the OR but then we received a call. Dr. P was here and scrubbing in. With relief and gratitude, I started to cry. I was out before I even got to see her face, but I went out with comfort, knowing that she was there for me. Why did she come in on her day off? I'll never know, but again, I was grateful for the gift.

I woke up, and after a short recovery time, John helped me get dressed. When I stood, it felt like

nothing was holding my insides in and I felt a huge rush of blood leave my body. I decided that standing was not in my best interest and that walking out of the hospital on my own two feet wasn't possible at this time. A nurse transported me via wheelchair to our car and I was never more grateful for the help.

As my luck would have it, I miscarried again 5 months later. After my pregnancy losses, I thought to myself, "I'm not that strong, "I'm not that resilient," "I don't know if I can try again," . . . the list goes on. The truth is, I had been searching for control during a time in my life when I felt like I had absolutely none. For most of my life, if I set my mind to something, I could achieve it. Scratch that, more than achieve, I could excel. Not this time. I couldn't will this to happen and I couldn't will it to happen the way I wanted it to. I was in self-preservation mode, trying to safeguard my heart from experiencing the same gut-wrenching pain I felt the days I miscarried. The temptation to give up was real. I could avoid all the anger, angst, and sadness. I could go on living fully instead of living in limbo.

The truth is, there was plenty of evidence that I have done and can do hard things. Yet the idea of another pregnancy loss was just too eviscerating. But then I thought, what if I can? What if I could push through again? What if I was actually resilient or strong enough? I'd never know if I gave up. I'd never know if I didn't try. Desperate for a successful pregnancy, I started taking a plethora of fertility supplements and going to regular acupuncture appointments. I set up appointments for John and me to meet with a genetic counselor, reproductive urologist, and two separate reproductive endocrinologists. I resigned myself to the in vitro fertilization (IVF) path and completely gave up on natural conception. There were no genetic concerns for us and John's appointment with reproductive urology was reassuring—there were no identifiable problems with his sperm. I concluded that it was my "fault."

Days before we met with reproductive endocrinology, I learned I was pregnant for a third time. I was convinced that I would miscarry again and proceeded with the appointments as if we still needed the specialty care. But with the support of supplemental hormones and close thyroid monitoring, I was able to hold on to the pregnancy. Today, I write



this narrative at 34 weeks pregnant. This pregnancy has been emotionally complicated as we navigate a way to be both grateful for the opportunity to be parents and grieve the losses we had to endure to get here. In fear that I might miscarry again, I resisted preparations for the baby up until recently. John and I still get misty-eyed when we talk about our journey to this point, and privately I can still cry hysterically over all the pain we've been through, but with time and the impending delivery of our baby, we are hopeful that our hearts will mend.



## The Mountain is the Valley

Reverend Shaina Rose Ciaccio

The phone shrills, interrupting my morning fog as I sip my coffee. The chaplain resident answers it quickly, her face growing serious as she listens. I scroll through my patient list for the day, taking notes on how many I can see today, not for medical care, but for various spiritual and existential crises. Checking into a hospital is anxiety-inducing, and so we provide what other medical providers can't do when they are crunched for time: our presence and a hand to hold, although that's changed a bit since the pandemic struck six months ago.

After hanging up the phone, my co-worker says slowly, "It's a stillbirth. And the mom is asymptomatic Covid positive."

She looks at me meaningfully.

"Do you want to be the one to go?"

I look at her, understanding, yet not understanding. I know *why* she's asking me. But I don't understand if I'm allowed in to see her. The policy is strict: essential medical personnel only for Covid positive rooms, and we chaplains don't rank high enough. We make phone calls instead.

Sometimes exceptions can be made. Based on the nature of these circumstances, a case could be presented for an in-person chaplain presence. Stillbirth is unlike any other tragedy because it's supposed

to be a time of great joy and expectation when you check into the hospital to deliver your child. There really are few things more sorrowful in life than the sudden and unexpected death of your baby.

I would know.

I came to this hospital specifically to do this work; to be with people in moments of hopelessness, because I understood what it was like to lose everything. The best chaplains around are that way because they too know what it's like to have traveled to hell.

I had always wanted to be *the* chaplain to respond to a patient and child stillbirth. Actually, I was desperate for it. I left my job at the state with its cushy benefits and security to pursue the call to care for others, and I wanted to be the one who sat with someone who lost a child too. My loss would mean something. It had to.

Approval was granted, and with precautionary measures in place, I began my ascent to the room. Stuffing my hands into my pockets, I fingered the small bottle of oil that I brought to anoint the little boy who had already departed this world.

I navigated the hallways easily, as I knew the way since I had also given birth to my subsequent living children on the same floor. Once upstairs, I met with the nurse who began to fit me with protective gear. I stopped for a moment, surprised, because . . . I remembered her.

It was past midnight, and my newborn son began to wail in his hospital crib next to me. It had been a year since my first son passed tragically, and the pediatric nephrologist had come in earlier with concerning news about fluid buildup in one of his kidneys. After he left, I picked up my son gently, and suddenly, began to sob uncontrollably. My body shook violently as I clutched my son to my chest. The nurse came in, alarmed at the scene before her. Between heaving breaths, I told her about my first son, and the nephrologist's news.

Sobbing, I wrenched out, "I can't go through this again. Do you understand? I can't lose one more. If I do, I want them to bury me too. I cannot live through this again!"

Between soothing words, she eased onto the bed, her arms wrapped around me and my baby, holding us tightly. A tiny island of grief, anchored in that moment by one touch.

In amazement, I watched as those same arms tied my protective gown behind my back, looking at me with kind and knowing eyes. As she tightened the knot, she murmured that except for the doctor and nurse, all other care this patient had received had been via telephone and she had no visitors due to the isolation status.

When you lose a baby, no one tells you there is more than grief to attend with. When your child dies, a thick and invisible barrier grinds up from the ground that divides you from the rest of the world. As I smoothed my hand over the door handle, I was reminded that some walls are real.

Stillness.

The room is silent, dark. The shades closed. There is a small shadow in the back, looking down.

*I understand.*

The voice in my head whispers as I give my name and announce that I've come to sit with her and bless her baby. I see her nod and I ease into the chair next to her, falling into silence. At some point, my gloved hand encases her small one. I'm reminded of the book of Job, that when Job had lost his house, his livelihood, and his children, his three friends first sat in silence with him for seven days before they spoke. They hadn't gotten everything right subsequently, but in this, they knew what it was to offer true comfort—a presence in the dark.

I ask to hold her baby, and we talk about his name and hopes and dreams for her boy. His skin is a rich mocha, his eyes framed by long lashes. He has a small mouth with a perfect bow. He's dressed in a white suit, and a blue bow tie adorns his neck. He is silent and cold and earthshakingly beautiful. I stroke his hair, marveling at the softness. It reminds me . . .

I shake my head violently when the nurse asks if I want to see my baby. The fear strangles me. At 23 weeks, I'm afraid of what I will see. With his size and genetic condition, I don't think I can handle another seismic shift of dreams being shattered. Yet sometimes, I wonder. I thought it was the right thing to do. But I never got to see him in the clothes I had bought the week before.

His mother weeps as I ask permission to baptize him, and she thanks me with her tears. I take out

the oil, placing a little dab on his forehead, making the sign of the cross. I pray as I anoint him, blessing his life and his mother, who told me that all she ever wanted in life was to have a child. I take her hand again and I pray for her that God would feel present to her in her moments of despair.

We embrace after. It's breaking the distancing protocol, but it feels like a sin not to provide the comfort that sometimes only touch can give. She looks into my eyes and gives me a wobbly smile.

"My faith is strong," she tells me. "I know for sure he is in heaven. We will see each other one day."

I had never believed in God before my loss, although I had performed my Catholic sacraments dutifully as a young child. Yet I found myself gripping the nurse's arm and asked her if I could see a priest. She nodded, and I wondered how often she cared for someone like me: a patient on a maternity ward with no child.

Another woman entered my room an hour later, and confusion set in. She called herself a chaplain, a word I had never heard before. Instead of a priest performing a ritual, she bent over my bed, her hands cupping my cheek as I wept, choking out words of shock. My husband sat in the chair, his head in his hands.

Words came, tumbling out before I could hold them back, "Do you think there is a heaven? If there is, will I ever see him again?"

A movement out of the corner of my eye saw my husband's shoulders shaking silently in response. She took both her hands, covering mine, with confidence and assurance that she knew he was there. Through the horror and confusion, this was something.

Something to hold onto.

Hope.

With one last hug, through my N95, I kissed her son on his forehead and placed him gently back into his mother's arms. She thanked me profusely for coming in, especially to an isolation room and felt comforted knowing that her son was baptized and her sorrow had been held.

I removed my protective gear in the bathroom, noting the angry crisscrossing lines across my face where the tight mask and goggles had bit into my skin. Sweaty and flushed, I slowly sunk to the floor, my head in my hands.

I had done it.

It had happened.

All the grief work, coming to faith in God, the birth of my subsequent children, and the loss of my son that I still carried, had been waiting for this. That I would be the chaplain that would carry the redemption for someone else that I still was seeking so desperately for myself.

I closed my eyes, searching for my feelings. Where was the satisfaction I was expecting to feel? There was sorrow over what had happened to her, and to me. There was the emotional toll of exhaustion and there was gratefulness in being able to be present with her. But the resolution I had been seeking was not there.

A week later, I shuffled into the group education room, a space where my peers and supervisor would go over our work, sharing our own life experiences alongside how we cared for our patients. I would be speaking today on the stillbirth visit, an especially charged moment since they were familiar with my story and why I had chosen the chaplaincy path.

They looked up expectantly, eyes full of care as I detailed how the visit had turned out. Near the end, I cleared my throat, prepared to take a risk, and said, "I thought that being the chaplain to a mom who experienced stillbirth would be a pivotal moment in my life. After leaving everything behind to pursue the call, I wanted his death to mean something. It was supposed to be like climbing a mountain, that when you reach it and look down, it would make sense. The loss of him defined me for so long—life before, life after. But when the visit was over, I felt grateful, humbled, and sad, but I didn't feel like this was the end. There is more to my journey. Somehow, there is more of me than just the death of my child. My time spent here has made me slowly realize this, but it's also been a time to slowly discover myself again. There is more life to be lived."

My supervisor stood up suddenly, scattering his papers on the floor. I stood, wobbly, and he held out his arms and pulled me into a tight embrace.

"I am so proud of you," he says while my peers begin wiping their faces with tears. In this moment, I am held.

I am held by the nurse, all other moms who lost their children, my chaplain friends, my supervisor, and by God.

And in this moment, I know for sure.

There is more.



## What Joan Marie Taught Me About Life, Loss, and Love

Rose Bendas

A scene from October 17th, 1989 is etched in my mind: my doctor entered the room excitedly saying, "Seven weeks left, let's hear the heartbeat!" As the stethoscope skipped around on my large tummy, I could see the doctor's expression drastically change to a solemn distressed look. Not saying anything, he put down the stethoscope. I earnestly kept asking questions until he finally looked me straight in the eyes.

"Your baby may be dead." Just like that.

He went on to say that an ultrasound would be needed to home in on my baby's heart. Both of our eyes drifted to the wall clock in the room, 4:55 PM.

"The technicians are gone for the day," he said and explained that I should come back with my husband tomorrow.

"What do I do now?" I asked. He told me to go home, rest, and there will be more details the next day.

I was more practical than emotional, and still hanging onto the hope of a healthy baby. I went back to my office to finish a report that was due the next day, knowing that I would be calling in sick. When I got home, I forced myself to empty the dishwasher and eat a grilled cheese sandwich. Afterward, I retreated to bed and kept the nightstand light on. I prayed intensely throughout the long night.

My husband and I had opposite work schedules. He worked 12-hour night shifts. I did not call him at work because I would have told him the truth and I was scared for his safety if he rushed home to be

with me. My husband, after all, should be the first to know, so I called no one. Not our parents or even a friend. At 6:00 AM the following morning, he found me sitting up in bed with the lamp light still on.

"Are you afraid?" he asked.

"Yes," I blurted with surprise. How did he know?

He started talking about a devastating earthquake in San Francisco, something that had been all over the news since last evening. I hadn't turned on the television, so I knew nothing of it. When he finally stopped talking, I shared our own horrible news—and then there was nothing to do but wait for the afternoon ultrasound.

We could tell by the technician's gasp that something was drastically wrong.

"I hear a heartbeat! Is that the baby's?" My husband was hopeful.

"No, that is your wife's," was the quiet reply.

The ultrasound went quickly, and then we had to wait an agonizing hour-and-a-half until the doctor could meet with us to tell us what we already assumed. There was no sign of life; our baby was dead.

"What do we do now?" I asked. "Can I be induced?"

The doctor explained that it was best to wait until my body went into labor naturally. He said it could be another week or two and to be prepared that the baby may be discolored or purple from lack of oxygen. Then he gave us time alone. I remember my words to my husband as he held me tightly in his arms. "I can live without this baby now," I told him, "As long as I'm pregnant next year at this time."

Waiting for my body to go into labor made no sense to either of us. I did not want my husband to see my basketball-size tummy anymore. Luckily, labor started naturally that night. We returned to the hospital and at 2 AM on October 19th, 1989, at 33 weeks, I delivered a little under four-pound stillborn baby girl with ten fingers, ten toes, and not discolored. My husband later told me that he thought that she would cry at any time because she looked so perfect. But no. There was total silence.

When the doctor said to be prepared that she may be purple or discolored, I made the decision not to see our baby girl. My dreams at night were so vivid and colorful in my pregnancy. I wanted

to picture a healthy baby in my *next* pregnancy—I didn't want images of a stillborn in my head. My only request was to have her baptized. Neither the doctor nor my husband told me that she didn't come out purple or that she looked normal—just that she was tiny. I am not upset with them because I made the best decision, at that time, in thinking of a future, wished-for baby. My husband was so strong for me that day, protecting my fragile emotions. I will forever be grateful to him for that.

The nursing staff was excellent. They had reminded me of the Lamaze Birthing Classes we had started only the week before—and they helped me breathe through the contractions. After the painful stillbirth with no medication, they kept me overnight for observation. They sent my husband home alone to an empty house. When he picked me up the next day, hospital staff wouldn't let us leave until we spoke with a hospital counselor. It seemed like it took forever for the counselor to arrive. We just wanted to go home! Finally released—and wearing the same lavender maternity dress I came in with—we held hands, walking down the loneliest, longest, dreary hallway. (I did not want to go out in a wheelchair). We were filled with loss and despair.

At the follow-up appointment, the doctor explained that I had a placenta infarction, meaning the placenta deteriorated but did not separate. We wanted to know the chance of it happening again. Further testing included a dye injected into my uterus to see if it was "heart-shaped," which it was not. My uterus was not malformed and other blood work checked out normal. We were referred to an OBGYN-specialist who concluded that the tragedy was just a "fluke" and that we could try again. The doctor suggested waiting 3-6 months for my body to recoup.

We waited six months before trying for another baby. Each month I did not conceive was especially discouraging because pregnancies and newborns surrounded me. My sister-in-law, one of my close friends, and six other ladies in different departments at work had all been pregnant at the same time I was before the stillbirth. It was difficult to return to work with co-workers bringing in their beautiful newborns. The clincher that made it

almost too much to handle was when my boss and co-worker both shared that they were pregnant. Then my sister-in-law had her baby girl. I was surrounded by the subject of new babies and pregnancies all around me. It took months to realize that I had to be happy *without* a baby before we would get pregnant again. I conceived our second child on October 19<sup>th</sup>, a year after losing our baby girl, Joan Marie.

The second pregnancy was going along smoothly until 32 weeks when I started having preterm labor. I was referred to the same OBGYN specialist, who explained that there are two types of placenta infarctions. One involves chromosome deficiency and a physical visible handicap, which is not the case with me. In the second scenario, the baby's heart stops for no apparent reason and there is no test available to discover if anything is wrong in advance. The specialist told me I had a 70% chance of it happening again. My husband and I were in shock and prayed even more fervently. We didn't know how we would survive the heartbreak of losing another baby, especially with two other babies expected near my due date by other family members.

At 37 weeks, I gave birth to a healthy 6 pound, 14 ounces, 19.5 inches baby boy with lungs fully developed. However, it was a scary "roller coaster" labor. The day started with my husband coming home from work at 6 AM and me telling him, "I think it's showtime." After his twelve-hour shift, my husband made the one-hour drive to the hospital. He sure knew the way—we had been there several times already with preterm labor scares, where each time, they administered medication to stop the contractions. At 1:00 PM my body wouldn't stop shivering and I couldn't stop vomiting. The nurse and my husband went back and forth from my bed to the sink, emptying little containers of vomit. Suddenly the nurse calmly asked me to turn on my right side, explaining she was giving me oxygen. I heard the call for Code Blue through the hospital speakers, not thinking it was me in trouble because my nurse was so calm and composed. My doctor came in, also calm, and asked me to get on all fours so he could check the baby's umbilical cord. When he finished, I turned around and was flabbergasted to find the room completely full of

staff and doctors. It was a learning hospital. The doctor told the crowd that the baby's heartbeat was lost, and he had checked if the umbilical cord was wrapped around baby's neck. They had given me medication to stop contractions and, he explained, that if it happened again, they would take baby by cesarean section.

They were considering medication to induce labor, but my body resumed labor naturally. After a lot of pushing, our healthy little boy was born. We have a niece that was born earlier that day (the two cousins share a special bond) and another nephew born at the end of July. We were all elated with healthy babies.

Each pregnancy is different, and complications can occur quickly. The pain and mourning process of a pregnancy loss, no matter how far along, is definitely a real loss. Family and friends try to offer comfort and support but don't know what to say. We heard all sorts of comments. "Oh, she really wasn't born," "You didn't know her," "God gives you only what you can handle," "It's been three months and I can see you are still hurting," and many more. My own mother was sad to see me grieving and hurting. I realized that I was still her baby and it hurt her seeing us in pain. This helped me realize I had to be happy with circumstances as they were. I took one day at a time and many times one hour at a time and—even sometimes—one minute at a time. Fortunately, my husband and I were strong together and still are. We read the book *When Bad Things Happen to Good People* and another one about someone's pregnancy loss. Both books were gifted to us. We decided not to attend a support group because we didn't want to hear heart-wrenching pregnancy loss stories. We wanted a positive way to process the loss of our baby and to move forward. Reading about and understanding the stages of grief after a loss was the most helpful to us: denial, anger, bargaining, depression, and acceptance.

After the stillbirth, I remember being angry at myself for not calling the doctor's office between my two-week appointments. I questioned my own judgment when I replayed a conversation I had at 31 weeks with a new OBGYN in the medical group. I told this new doctor that I didn't feel movement,



but she assured me that baby's heartbeat was fine at 170. She said I just had a quiet baby. I remember wanting to call a week later but thought, "What would I say differently and what would the doctor say differently?" A friend of my Mom's told me that her first baby hardly moved, and with this information, I decided not to call. *Of course*, looking back I wish I had called, that the doctor had done more testing, and that I could have seen my usual doctor for each appointment—not a stranger in the practice. I couldn't help thinking if I had all my appointments with my primary OBGYN doctor, since he knew the history of severe cramping at the start of my pregnancy, that he may have treated the situation differently when I expressed my concerns.

There are all kinds of grief. Seven years after my stillbirth, I lost my mother to colon cancer. Two weeks later, my oldest brother died from a brain tumor. I cared for my father as he grieved for his wife of 43 years and the loss of his first child and also supported my sister-in-law while her children sobbed for their father. I used my experience of the grief process to support and help them. When we lost our first baby, I knew there had to be a reason for our loss, but I was not sure why then. The stillbirth had prepared me in some way to understand others when dealing with death. I feel I can show more empathy, knowing that all their feelings are legitimate. I know just to be with them and hear them out without discounting their feelings but impart guidance not to dwell in sorrow.



### **Helping Loss Parents Heal After Miscarriage: The Critical Role of Medical Professionals**

Monica Snyder

**I** have lost two children early in pregnancy: Scout and Hank. These losses took a significant emotional toll on my husband and me, and our experiences were worsened by well-intentioned but

ill-equipped, uninformed professionals. I hope the medical community can learn from my experiences to better support other loss parents.

#### **Scout**

In early 2019, when pregnant with my third child, I opted to get the 13-week ultrasound, a non-routine test to detect potential genetic anomalies. During the test, the technician asked if I was aware I had a twin pregnancy. I was not. My OB had told me this was a singleton pregnancy. The technician explained that there had been a twin who passed away, probably around the 6-week mark, and that my body would reabsorb the remains of the twin. Shocked and uncertain, I calmly asked her to elaborate, and she detailed the signs that there had been a twin rather than a blighted ovum or placenta outgrowth. She mentioned she was willing to give these details because I seemed "very reasonable," unlike moms in the same situation who "really freak out."

I was surprised at the intensity of my grief. If I hadn't opted for the 13-week ultrasound, my husband and I would have never known this child existed. As it was, we didn't learn the child existed until weeks after he or she had died. Nevertheless, my grief was sharp and painful.

I found myself craving ritual and acknowledgment but not knowing how to fill those needs. We chose a unisex name: Scout. I bought an engraved memory box, but I didn't have much to fill it with. I have the one blurry ultrasound photo of the gestational sac long after the child had passed. Otherwise, I filled the box with cards, pressed flowers, and other memorial tokens sent by loved ones.

I felt confused and untethered, my mind filled with catastrophic thoughts. I decided to seek grief counseling. Our health insurance provider required that I get assessed before referring me for counseling. At the mental health clinic, the psychiatrist assessing me explained that bereavement isn't a mental health disorder, and so the clinic couldn't offer me many resources. I countered that I wanted only to see a grief counselor. She said a referral would take a week or two to go through, after which I would have to call clinics myself to find a good fit. I

agreed and asked her to start the process. She added that it was normal to be upset since it had been only a week since the miscarriage but that it sounded as if I already had a good support system. She seemed to be trying to talk me out of pursuing counseling. I reiterated that I wanted to see a grief counselor, and she gave me a referral. Still, I was taken aback by how aggressive I had to be to get help.

The referral went through weeks later, but I still wasn't able to see the counselor I chose because she required an authorization number from my insurance provider. I left multiple voicemails and emails requesting the number but getting no response until I filed a formal complaint. The entire process took months of persistence, all when I was already psychologically exhausted.

The first counselor I saw noted how early my pregnancy loss was, a common remark that tends to undermine loss parents' grief. The counselor also repeatedly suggested that my grief over Scout might be only a surface emotion for deeper, longer-term issues in my life, seemingly implying it was abnormal to grieve this hard over just a pregnancy loss. Near the end of our first session, she remarked, "Well, I'm glad to work with you on processing your . . . well, I guess it's like a miscarriage, isn't it?" I did not continue to see her.

I did join pregnancy loss groups online, which helped significantly. However, it was disheartening to see so many grieving women also struggling with profound feelings of isolation. They reported countless comments from friends meant to be comforting but often quite hurtful: "At least it wasn't a real baby." "You can always have another." "At least you know you can get pregnant."

Fortunately, my social circles were far more supportive. And I'm very vocal about how I'm feeling and what I need. While my husband and I were processing this loss, our family and friends came around us, sending memorial gifts, cards, and flowers; regularly checking in to see how we were doing; using the name of our child and humanizing him or her; and generally marking the gravity of the loss. It helped.

Still, the rest of the pregnancy with the surviving twin was under a dark cloud, and when I birthed

my son I was filled with a bittersweet mix of great joy to be holding him and great sorrow that Scout wasn't with us.

## Hank

For most of my adulthood, I've hoped for four children. Though the loss of Scout was devastating, I knew that frequently pregnancies with multiples have complications and that those complications don't necessarily mean an elevated risk to getting pregnant again. So we did get pregnant again in spring 2021. I was happy but also anxious. My first trimester symptoms seemed milder than those of my prior pregnancies. I tried to wait patiently for the initial prenatal appointment without worrying about what I couldn't control. It was difficult to do.

When my husband and I finally went to the appointment, I knew something was wrong by the way the OB spoke. With my prior pregnancies, she referred to the child as a "baby," "little peanut," or other colloquial phrases imparting affection and value. But as she conducted the ultrasound for this child, she was quieter. She said she wanted to make sure she could clearly see the "fetus." I stared at the office ceiling lights, wondering how long these moments would drag on.

Then the OB told us: she could not find blood flow or a heartbeat. I swore and started crying. My husband teared up too, stroked my hair and held my hand.

This loss was a missed miscarriage, meaning my body had not naturally passed the remains. My OB told me that I could wait to see if I passed them naturally or I could take certain pills or undergo surgery to remove the remains. I had hoped to leave that appointment joyously announcing our pregnancy. I had hoped to provide a safe, nurturing environment for our family's newest sibling. Instead, we headed home to discuss how to force my child out of my body.

We chose the surgery, which was scheduled for a week later. From our experience losing Scout, my husband and I knew we needed to have ritual and acknowledgment to process our grief. For this loss, there would be remains. We wanted to have

them genetically tested for any insight about why I miscarried and then cremated and sent home with us, a physical testament to this child's existence.

Although the healthcare providers were not resistant, they didn't seem to know how to fulfill our requests. I believe if I were a less aggressive person or had fewer resources and advice from experienced friends, we would not have been able to handle this emotional crisis the way we wanted to.

There were four points at which our goals could have been thwarted:

First, when I asked my OB if the hospital could release the remains to us, she apologetically but firmly said no. But when I asked the surgery scheduling nurse the same question, she said it depended on which surgeon was removing the remains. Apparently, some surgeons know how to preserve remains for cremation, while others do not. The surgeon assigned to me called later to say she could save the remains. I was relieved but also noted the contradicting answers of the OB and surgeon. If I hadn't asked a second time, I wouldn't have known cremation was possible.

Second, the surgeon told me we could not have both genetic testing and cremation because the testing process renders the remains ineligible for release. I asked if the remains could be split, with a small sample for testing and the rest for cremation. The surgeon said she didn't know but would find out. She called me back promptly to say that, yes, it could be done. I was grateful, but again she initially gave me incorrect information. I knew from my work in a forensics lab that it takes very little sample to conduct genetic testing, but without that background, I would again have thought our goals weren't possible.

Third, through discussions with a friend who also experienced pregnancy loss, I learned many hospitals won't release remains unless parents have processed paperwork with a funeral home in advance of the surgery. No one at the hospital had mentioned this, but when I arrived for the surgery, they did request paperwork. If my friend hadn't forewarned me, it would have been too late to set up the release.

Fourth, to further complicate our situation, my husband, three living children, and I were moving out of state two weeks after my surgery. The funeral home needed us to get the remains to them promptly so they could complete cremation and release before we left. On the morning of the surgery, I asked the prepping nurse if the hospital lab could expedite the processing and release of the remains. She said expedited service wasn't possible with so many other samples from other procedures submitted before ours. Nevertheless, when the surgeon came to discuss my procedure, I also asked her about expedited service. She asked another nurse to check with the lab. The lab quickly confirmed it could move our sample to the "front of the line" so the hospital could release the remains to the funeral home that same day. Again, I was initially given incorrect information. If I hadn't asked a second time, we might not have been able to get the remains before we moved.

This level of persistence shouldn't be necessary. Many people are not as insistent as I am, especially in the midst of grief and unfamiliar circumstances. Most parents would naturally assume their medical practitioners correctly understand hospital protocols and so would have given up on options that could have helped them heal. I've talked to many loss parents who lament not asking for the remains, as well as those who did ask only to have the hospital refuse release. These stories are filled with regret.

I have a good community around me. My friends and family were very supportive, and I found solidarity in online pregnancy loss groups. In contrast, the interactions I had with professionals left a lot to be desired. But it would not be difficult for the medical community to better serve loss parents.

Hospitals should train staff on available legal options and the steps necessary to streamline them. Staff should present these options at the same time parents receive news of the loss. Staff should be trained to recognize that pregnancy loss may be an emotional and psychological crisis, even if not a physical one. Research has shown that small steps, such as offering to create memorial gifts or



referring for grief or spiritual counseling, serve to acknowledge the gravity of the loss and the validity of the parents' grief. Such steps make the grief shorter-lived and less intense.

In the end, we were able to get our child's remains tested and cremated. The testing revealed he had been a boy. We named him Hank. Testing also indicated Hank had a trisomy on his 16th chromosome. This information was a small comfort because trisomies are spontaneous genetic events. They don't indicate ongoing physiological problems or increased risk of miscarriage. This information informed our decision to try once more for a fourth child, and as I write this, I have recently delivered my newborn daughter.



## Primigravida

Jessica Bratt Carle

I now have two sons, ages four and one. In 2016, however, my first pregnancy ended in miscarriage at ten weeks gestation. As a seasoned hospital chaplain in my late 30s, I was no stranger to medical settings and terminology, nor to death, grief, and the myriad ways people deal with unexpected sorrow. I was comfortable being present to other people in some of the worst moments of their lives.

But when I suddenly found myself as the patient, the bereft would-be parent, there was nowhere for me to hide. My familiarity with the healthcare system didn't do me much good—no clinical observations or detached analysis were going to help me muddle through the emotional soup I was experiencing. Everything I went through at that time felt raw and immediate. I felt bewildered on the receiving end of the healthcare system. Its personnel and processes felt cold and harsh when I most longed for compassionate care and deep human kindness.

When I found out I was pregnant, I had done my homework, trying to find just the right OB/GYN. We had been living in our city for less than a year and I hardly knew where to start. I'd settled on an OB who was a young mom of three herself and seemed approachable and well-trained. When we showed up for our second appointment with her, I had been bleeding for a few days and was worried I was miscarrying. The ultrasound confirmed this—where we hoped to see an amniotic sac and a little tadpole figure of a baby, there were only scattered blotches that looked like a deflated balloon. I'll never forget that image.

My doctor was effusively chipper in the exam room, asking me questions like "How was your holiday!" when I thought I had already explained that I'd spent the 4th of July weekend on the couch, bleeding and cramping. My husband and I had tears brimming in our eyes, but her perky demeanor persisted. "So, when did you start bleeding!" she continued brightly, but by then, it felt like we were conspiring to act curious about something whose outcome was already sealed. There were some statements about how common miscarriage is, how seldom people find out a cause, and some guidelines for what to expect as my body expelled the pregnancy. I was relieved I wouldn't need a D&C procedure; she expected that I would miscarry naturally and might perhaps only need some medication to help things along. I was provided a prescription and that was about it.

Her affect seemed incongruent with the situation, but I wonder now, what would an affect congruent with the situation even look like for a provider who sees this kind of thing so routinely and is only given 15-minute appointment slots to tend to her patients? Was it unreasonable for me to want her to tend to my emotional state and show anything more than perfunctory empathy? My world had stopped, but hers had to move on to the next billable encounter. In hindsight, I suspect it would have taken a monumental effort for her to pause and adequately respond to me in the way I yearned for.

Healthcare keeps overloading its precious human resources with technology and documentation and

revenue cycles, all in the name of patient satisfaction and safety, and we have become too accustomed to letting that overload undermine the very rich, meaningful human interactions that draw people into healthcare in the first place. What tasks and schedule constraints and efficient workflow processes would my OB have had to ignore to set aside her distraction and be present with my husband and me, even for a few minutes? To acknowledge the pain and shock we were experiencing, to normalize the grief process we were about to embark on, to demonstrate *care*?

The thing is, patients who are in unfamiliar territory are taking their cues from what's going on around them, trying to gauge a proportionate response. The implicit message I got from my OB was, *this is not really a big deal*. Like, note to self: it is not okay to come undone right now. But the future I had started to envision had crumbled like that heap of rejected womb contents in black and white on my sonogram. It would have meant so much to have some acknowledgment that this experience was earth-shattering for me.

Instead, we numbly made our way to the check-out staff person, who cheerily asked if we were ready to schedule our next appointment. Clearly, despite all the technological sophistication of the equipment in front of her and throughout that office, no one had a system in place to flag my record and give the receptionist a heads up that we wouldn't be needing any next appointments. I mumbled quietly that I wasn't sure. It was so awkward. I wasn't ready to have people within earshot hear about my loss, and it didn't feel like this random person should be the first person I should have to practice saying it out loud to. I was just crushed. I just wanted to get out of that building, and yet another micro-opportunity for care and compassion had been missed.

I looked over my shoulder as we left, glancing at the snazzy decor and waiting room furniture, where just a few minutes earlier, a very different me had paged through a Babies 'R Us registry catalog and exchanged furtive looks with other women as we sized up the relative swell of our respective abdomens.

In the aftermath of the physical experience of the miscarriage, I struggled to validate that my loss was substantive. There's a real disenfranchising of certain kinds of grief, where it's easier to recognize the magnitude of some losses and minimize others. I was "only" ten weeks, early enough in my pregnancy where miscarriage is most common, yet this only complicated my grief. On the one hand, I knew I was in good company with plenty of other women who have gone through this. On the other hand, despite cultural norms shifting somewhat toward more openness in talking about pregnancy loss, I still perceived that an earlier loss like mine just wasn't that substantial; not quite as deserving of as much sympathy compared to the kinds of later pregnancy losses and infant losses I had all too often witnessed in hospital chaplaincy. I don't know if I was trying to comfort myself with this kind of comparative suffering. (How many times have I heard patients try to talk themselves out of their own distress by talking about how much worse off other people are?) Or perhaps I was self-conscious about my grief feeling somehow out of proportion. It was isolating and confusing. Maybe part of me genuinely hoped that if I could justify minimizing my grief, it would resolve more quickly.

It's become clearer to me over time that the experience of loss doesn't somehow get dosed in relation to the length of time you were pregnant or the time that you knew someone. It's about the relationship that is lost. Grieving a grandparent or a sister or a newborn is going to take shape based on the singularity of that person and the circumstances of their life and death, and will take as many shapes as there are mourners who had a particular, unique relationship to that person.

For me, grieving my early loss not only meant letting go of all the possibilities for the future of that relationship and that baby, it also meant grappling with my deep fears that this was going to be the beginning of a long arduous journey toward parenthood, just when I thought I'd lucked out by being able to get pregnant in the first place. I knew that having had a front-row seat to the utterly traumatic experiences of so many other people, I could all too

easily catastrophize even the best of situations by dreaming up all that could go wrong.

I had to make space for my loss to come into its own, and this turned out to be a process whose timing I couldn't speed up by my own volition. My loss gestated too, developing in identity and its impact on me as I surrendered to its unfamiliarity. I didn't know what my loss would grow into any more than I knew who that baby might have been. As I gingerly dared to imagine the possibility for a living child to come into our lives in the future, I knew it would be against the backdrop of this tender first chapter. No matter where my eventual path to parenthood took me, it had begun with a painful letting go.

I had to let go not only of the baby I had begun to love, but also of my nascent self-concept as a mother. At the time of my miscarriage, I'd known I was pregnant for about five weeks. During that time, the daunting reality that my body was playing host to another person's life was never far from my mind. From that very moment after watching those pink lines show up on the pregnancy test on the bathroom counter, I began adapting my decisions and mindset to this all-encompassing reality. Forgoing the hot tub, the drink at the wedding we attended a couple of days later, thinking twice about lunchmeat on my sandwich, googling daycare possibilities, holding off on buying new clothes and searching for maternity clothes instead, mentally mapping out the timeline of whether we could still take planned travels several months down the road, booking that dental appointment because I'd read that getting your teeth taken care of during pregnancy was really important (who knew?). There was no baby bump yet, but there were the beginnings of the same mindset of responsibility and connection that I perceive daily in myself now that I am parenting two children. My counselor later helped me explore the concept of matrescence, how we grow into our sense of motherhood gradually and not instantaneously. I may have only been ten weeks along, but my mind and heart had turned their attention to all that this new role and identity would ask of me. When my uterus said "never mind" to that first brief pregnancy, the possibility

for that baby left my body, but the mother in me had already taken root.



## I Adore You

Angela Yvonne Dahm

**M**y son, Theodore, was conceived after attending a cousin's wedding in Madison, WI. That cousin now has her own sons, one of whom is named Theodore. I found out I was pregnant on the first day of September and felt overwhelming excitement and anxiety, all at once. Would this pregnancy end happily for us? Two years earlier, we had lost our second pregnancy at 12 weeks because the fetus was not growing properly. The pregnancy was not viable, however the hospital was prohibited from performing a D&C because a heartbeat was still present. As a result, I remained hopelessly pregnant for three more long weeks waiting for that heartbeat to stop. Those three weeks were excruciating and traumatic. I grieved this loss deeply.

Pregnant again, I cautiously took it one appointment at a time. Each *whoosh whoosh whoosh* of the heart doppler offered new hope and excitement that our baby was going to come to us. First trimester, then second trimester, then third trimester, but in the end a live birth would not be ours. The 27-week appointment went off without a hitch; a strong heartbeat, lots of baby kicks, round ligament pain, and complaints of swelling. I was anxious about traveling on an airplane for our upcoming baby moon<sup>1</sup>, so my doctor had me return in three weeks so we could check on baby boy before we flew to Dallas, TX.

Three weeks later, a couple of days before my scheduled appointment, I noticed decreased fetal

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<sup>1</sup> A baby moon is a trip or vacation taken by a couple shortly before the birth of a child.

movement and called my doctor's office. While initially telling me I might need to go to the hospital for fetal monitoring, the office called back to let me know that I was to count kick cycles that evening and come in first thing the next day. I had an anterior placenta with this pregnancy, which meant that the kicks were softer, as there was an entire placenta to send the kick movement through before it reached my belly button. I counted some kick cycles and fell asleep. Little did I know the devastation, pain and loss I was about to encounter.

The next morning, cell phone in one hand, milk and decaf coffee in the other, I happily plopped down in the office, ready to get cozy, send some emails and listen to my baby's heartbeat. As the nurse tried to hook me up to the fetal monitoring machine, she struggled to find a heartbeat. After several minutes, she left the room to get help from the nurse practitioner. "She doesn't know what she's doing," I thought to myself. When the nurse practitioner couldn't find the heartbeat either, she left the room to grab a different doppler machine. When that proved fruitless, I told her, "This is bizarre. Dr. M always gets it on the very first try." She told me that I would need to go to the hospital for an ultrasound to check on the baby. She left the room to schedule the appointment and returned to let me know that I had an appointment and needed to go straight there. I broke down in tears in the elevator when I called my husband Jonathan to let him know that they couldn't find the baby's heartbeat and asked him to meet me at the hospital for an ultrasound.

While driving, I called my mother, who was aware that I was going to the doctor to be monitored. She wanted to come join me at the hospital and I declined. I texted a couple of friends to let them know what was going on. When I got to the fourth floor at the hospital, I checked in and the receptionist told me I would need someone to accompany me for the ultrasound. That really set me off. I told her my husband was on the way and she asked that he check in at the front desk when he arrived. Why did I need someone to go back with me? I called my dear friend, Hannah, and cried and cried while sitting in the waiting room.

Jonathan arrived, checked in, and they escorted us back immediately. The ultrasound felt surreal. I was in disbelief that we were even having one in the first place and held hope that the image would show everything was normal. Even if we learned it wasn't normal, I never in my worst nightmares could have been prepared for the excruciating news we received: our baby boy was dead.

It was the single most painful moment of my life to learn that my baby had passed away. To go from such happiness and anticipation of a new baby to the debilitating despair that my child died in utero—a part of me died with my baby boy that day. We left the ultrasound bereft and went home to digest this new reality, call family, pick our daughter up from preschool, deliver the heart-wrenching news that her baby brother died, and pack our hospital bags for my induction that same night.

Labor was initiated by topically applying a medicine to thin my cervix. It was nighttime and I was administered Pitocin intravenously and upped the dosage regularly to get labor going. I think we must have slept. By morning I was talking to the doctor. Not my doctor; my doctor was off the shore of a distant island scuba diving. My doctor had another doctor covering for him. This doctor offered a Foley bulb catheter to deliver the baby as quickly as possible. The doctor assumed we wanted this nightmare to be over. From where we sat, in utter shock and despair, the Foley bulb catheter was definitely not an option. It turns out, this busy doctor was also teaching at a nearby university and had a very busy, full practice of his own. His lack of kindness and impulse to rush us through the process could not have hurt me more. Here I was at the most awful moment of my life and he made that moment worse for me. The hospital staff, however, took it upon themselves to send the Chief of Staff to offer their apologies and followed through by calling the doctor on a speaker phone to issue a formal apology to me and my family. The nurses couldn't believe how insensitively the doctor behaved.

After 24 hours of labor, Theodore John or "Teddy" was born at 11:20 pm on March 2, 2016 at 30 weeks gestation. He weighed 2lbs 5oz and was 14 ½ inches long. My husband and I delivered

him with a night nurse named Ann. He came so quickly, no pushing, just a long, low pressure, a primal urge, and a burst of great warmth. I said, "I'm scared to see him," and the nurse understood, but I changed my mind immediately and began to examine his perfect tiny body. Ten fingers, ten toes, my nose and ears, an unmistakable likeness to his father, soft blond curls on his sweet head. He was my little Teddy bear. Teodoro in Spanish translates to "I adore you," and yes, that was the feeling I felt while looking at my baby.

The morning after he was born, I awoke hysterically crying. My baby had been born. He was dead. He was no longer inside of me. He was here. He was gone. Miranda was my nurse that morning and she appeared to be an angel. She told me she had been in my place, in this exact room, and lost twin girls. She mourned with me. I felt the intangible presence of God in our shared humanity. That day, Jonathan wanted to go home, but I wasn't ready. He appeased me. The doctor said we could stay as long as we needed. The nurses said they would not kick us out.

Sherry, the hospital chaplain, came and mourned with us. My friend Megan came and brought Teddy a tiny blue hat that she crocheted while we were in labor. Jonathan and I showered and tried to put one foot in front of the other to figure out our next step. I texted my mother to bring our only child Eleanor up at 10 am. I called Jonathan's mother to come up at the same time. I arranged for the hospital volunteer photographer, Now I Lay Me Down to Sleep, to come at that time to take pictures. Jonathan was appreciative of this coordination. I asked him if our brothers and sisters could come for a short visit at 1 pm and, miraculously, he said yes. I quickly shot out that text before he changed his mind. We filled out the death certificate and autopsy report and arranged for genetic testing the day before, and there was blessed little formality to figure out, save for food.

When Eleanor came, I was so happy. I got out of bed and went to hug her. I told her I had Teddy. She wanted to see him. I immediately said yes, but I told her he "looks scary." When she saw her brother, she said, "Mom, oh he's *beautiful!* He doesn't look scary!" I felt my heart melt. This was the day Eleanor became a big sister. She showed up for her little

brother with grace and love. Jonathan was careful to offer her breaks and distractions with a coloring book. We gave her the teddy bear that Sherry, the chaplain had purchased for us the day before when she heard his name was Teddy and that he had a four-year-old sister. I read the book "Wherever You Are" to Eleanor in the hospital bed, and she crawled over to his bassinet every minute or so and held his hand and gave him kisses. She whispered to me, "I wish he was moving," and, oh, how I wanted things to be so much different! How I wanted Eleanor's baby brother to be *alive*, how I desperately wanted that for her, for all of us.

Then there was the enormity of grief and trauma. Every time the HVAC system kicked on at the hospital, I thought Teddy was breathing and momentarily lost touch with reality before remembering again. My mind, my body, my spirit all wanted to reject the pain of losing my baby. My milk came in. Everyone who knew me pregnant approached me and asked about my new baby. I had phantom kicks and often caught myself unconsciously waddling around, as if still pregnant. I needed help.

Help manifested in many forms. Cards and gifts came pouring in from our communities as everyone shared their condolences. Teddy's death touched hundreds of people—even people we had never met. Meals arrived in a cooler on our doorstep for two months. Family members came and sat with us so we wouldn't be alone. On Theodore's due date, my friend Ariel organized a group of women to walk around our block two times in silence, stopping in front of our home for a brief pause each time. By the end of the walk, my grief felt notably lessened, as if each friend there helped me carry a little bit of the load as we held hands. One of the biggest lessons grief has taught me is that I'm not alone, that social connection can foster healing, that there are so many parts of me and one part is a grieving mother. That part of me is in awe of my ability to love so deeply and fully. Teddy has shown me how I can hold more than one emotion at a time. Happy and sad. Grateful and bereft. Accepting and loving.





## The Value of a Life

Monika Jaquier

**W**hat makes the value of a life?  
The number of years it lasts?  
The number of things accomplished during this life?

One day, I was asked to decide.

"I am seriously worried about the head," said the ultrasound specialist, "your baby has anencephaly, the most serious birth defect of the brain."

In my head, I see the movie of our family's life: three small children who already draw a lot of attention and a disabled baby, appointments with doctors and therapist, a car big enough for the future wheelchair.

"And now?" I'm sure that he will now tell me about the surgeries and therapies that will fix my baby. "Your baby will die shortly after birth. There is nothing that can be done. You can still abort if you wish to."

What? How can this be possible? Miscarriages are a reality I've experienced twice, but once the fateful mark of 12 weeks passed, everything should be fine, shouldn't it? I just saw my baby at 22 weeks wiggle around in my womb, saw his heart beating, and over the appointments of the past weeks, I had been able to see my baby's growth.

I'm grateful I don't have to choose now in this moment of deepest shock. That the decision had already been made before this pregnancy even began, when my husband and I had discussions about what we would do if one day we got a poor prenatal diagnosis. While we were unaware of all the possible health issues, we made the fundamental choice that no matter what would be discovered, we wanted to value the life of each of our children.

I decline the doctor's offer and tell him that I want to continue the pregnancy to give our baby every possible day of life and love. He accepts my decision without arguing but gives me his phone number to call whenever I'd have questions.

Not everybody respects our point of view. Two weeks later, I'm back at my OB/GYN's office; in the meantime, he got the report from the specialist. He tells me that this pregnancy should not last a

day more, that I should stop it and start again with another baby that is worth it. In his eyes, my baby has no more value than an earthworm. He must never have heard of non-directive counselling . . . The only positive aspect of the appointment is that I learn that I'm carrying a little girl.

It's not the last time I have to find answers to the question, "What is my baby's life worth?" Family, friends, health care professionals, and even people I've only met a few instants ago "know" what I should do. I realise nevertheless that the opinion of thirds has not much importance, as we will have to live the rest of our lives with our decision, not them.

My daughter did not change with the diagnosis. She had almost always been like that, as this birth defect appears in the first weeks after conception. What changes is the way she's seen now. To my husband and me, she's our beloved daughter, growing and developing in my womb, reacting to our voices. To our children, she's their little sister who will stay for just a short time. To others, she's just worthless.

During the first days after the diagnosis, I struggle with the fact that I have to know about our daughter's upcoming death, with the responsibility for my baby's life, and the judgement of people around us. Wouldn't it be much easier to ignore everything and just enjoy the pregnancy? But with the weeks passing, I become increasingly thankful for the opportunity to prepare and live mindfully during the time of our daughter's life.

So we decide to make the best of every day we have with her.

First, she gets a name: Anouk.

We try to bond with her through little things such as reading books to our children before they go to bed, as well as through special trips like going to the circus, the fair, or the mountains.

It's a bittersweet time. Sweet because there is so much life, hope, and love to share in an apparently hopeless situation. Bitter because we realise too often that it will be the only time we'll be able to experience this with Anouk.

During the regular appointments with the (new) OB/GYN, the doctor's main focus is on answering my questions and, towards the end, on discussing our wishes for Anouk's birth and life. The concept of "perinatal palliative care" is not even known yet in Switzerland, where I live, but my doctor is doing

exactly what it entails: creating an interdisciplinary network of professionals around us, keeping everybody informed about our choices.

On her side, my midwife is helping me create a “bubble of normality” during the water-gym classes for pregnant women; how I enjoy this weekly hour where I can just chat about normal things of pregnancy with other moms.

Eighteen weeks after the diagnosis, on her due date, Anouk is born. The pain of the birth is excruciating. It feels as if the physical pain has been enhanced by the fear that the moment of her birth could be the moment of her death. So, when she starts breathing—once the midwife leads her to my arms—the world around us stops turning. Nothing else has any importance anymore. Our daughter has been born, and she’s *alive*.

The top of her head is covered by a little hat I knitted for her. We realize the reality of anencephaly, but in our eyes, Anouk is nothing but beautiful. We realise that there is no need for a perfect brain to be able to be loved or to love.

Our children come to meet their little sister, a meeting they will never forget; the pictures of those moments will be our biggest treasure.

It’s a time to celebrate. Thanks to the prenatal diagnosis, the biggest shock is behind us. We could prepare ourselves for this time; the joy of finally being able to take Anouk in our arms is overwhelming.

It’s a precious but short time. Anouk’s body was not made to last; we see it with our own eyes. When her breathing becomes slower and slower, we can tell her that we’re ready to let her go. She breathes once more and then dies in our arms. Like a candle flame that gently goes out, her soul leaves her body to join her heavenly Father.

The experience of her peaceful death will give me comfort and strength in moments of sadness ahead.

Anouk’s life lasted 40 weeks in my womb and 13 hours in our arms. Worthless for many; priceless for us.

I’ve never been more grateful for my living children than I was after Anouk’s death, as I know that nothing can be taken for granted.

Grief comes in waves; there are no shortcuts; it’s hard labour. I realise that I need to grieve for the

two little babies we had lost through miscarriage at the beginning of our marriage. When I lost them, people had told me just to move on, that I would have other children. Obviously, I did go on to have other children, but the wound in my heart their death made didn’t close alone. Just as for Anouk, I needed to value their existence, as short as it was, and to face the pain of their loss before I could let them go. It is not too late to do this, and I realise it sets me free.

It takes us a long time before we feel ready to try for another baby. This last pregnancy is an emotional challenge of its own. Thankfully my OB/GYN does understand me, and when he shows me the beautiful round head on the ultrasound screen, I’m sure he’s just as happy as I am. Despite the doctor’s “all clear,” the fear that something could go wrong doesn’t leave me until the moment I hold our healthy baby in my arms.

When people ask me today how many children I have during small talk, I usually say 4. Not because Anouk and the two little ones are not important, but because their importance does not depend on what others think and because a few instants of small talk are not enough to talk about all the blessings they brought into our lives.



## Losing Desiree

Sirena Washington

“Congratulations, Ms. Washington, you’re pregnant,” were the words that forever changed my life. After two years of trying to expand our family, our dream of becoming parents was finally here. We were preparing our hearts and our home for our baby, until our dream was shattered.

In June 2007 (just a month and a half into my second trimester), I started experiencing cramps. I had hoped that the cramps would subside but instead, they became more consistent and unbearable. My partner and I decided it would be best for me to go

to the hospital. Nothing could prepare our hearts for what was about to happen next.

Arriving at the hospital, nurses met me at the door with a wheelchair telling me to breathe and that everything would be okay. When I arrived at the examination room, doctors were coming in and out, and I didn't know what was going on. (I was distracted by the pain.) While lying in the hospital bed, I prayed that everything would be okay. The ER doctor came in and out of my room several times to examine me, but I knew something was wrong when he came into my room with additional nurses. One nurse walked over to me and held my left hand, while another nurse came to my right side and placed her hand on my shoulder. The doctor stood at the foot of my bed, looked at me with a pale face and uttered, "Ms. Washington, you're going into early labor, meaning you are having a miscarriage. You have dilated 6 cm already. With you being only five months pregnant, you are going to have to deliver the baby. There is a 90% chance that the baby will not survive outside of the womb, but we will do everything we can. I am so sorry." Those words hit me like a ton of bricks. I turned to my partner and asked, "You mean our baby will die?" The words "will not survive" numbed me. As I lay in the bed trying to process all that the doctor said, tears filled my eyes. I was so numb; I didn't feel the tears roll down my face. Once the numbness wore off, I cried out, "God, why me?"

The doctors began prepping for the delivery. As I prepared to push, I begged God to let my baby survive. I even tried bargaining with God, saying that I would do better if he let my baby survive. Three pushes later, my baby was delivered. I waited for what seemed like forever to hear my baby's cry and to know that the doctors were wrong (saying to myself, "she's going to cry any minute because God wouldn't take a baby"). I never heard the "newborn cry" to tell its mother, "I am alive and okay." My baby passed away during the birthing process. After delivery, the nurses cleaned my baby, clothed her, and laid her in my arms, wrapped in a blanket. They said, "Ms. Washington, the baby is a girl. Would you like to name her?" I said, "Desiree is her name." I held Desiree's lifeless body in my

arms, hoping that a miracle would happen and that she would show some sign of life (after all, miracles happen every day). Nothing changed. That's when reality hit me; my baby was really gone.

I lost my faith and hated God for not finding me worthy enough to be a mother. I couldn't understand why this was happening to me. I was in the darkest place of my life while a thousand thoughts ran through my mind. I had taken care of everyone else's children most of my life, but God didn't think I would make a good mother. How? Why? This wasn't fair. How was it that I delivered a baby and wasn't able to bring that baby home? How was I going to keep answering the dumbest question, "Are you okay?" I left the hospital with a box of memories and a build-a-bear that held a recording of Desiree's heartbeat in it. The memory box and bear were great, but it wasn't my baby.

Losing Desiree was extremely hard. I didn't know how I was going to pick up and go on with life without the baby I had waited years for. I felt that I was being punished.

What made matters worse was when I followed up with my clinician. She made me feel as if I was just another mother who lost a baby, asking what my future plans were for kids, if I wanted birth control, or if I wanted to try again. In my mind, I was screaming, "What I want is my baby that God selfishly took from me! What I want is for you to know that I am hurting and that I am not okay. I am mad, and I am dying inside!" All I could respond with was, "I don't know what I want to do at this moment." My doctor said, "Okay, well, let me know if you need anything." Afterward, the doctor walked out. Why was she acting like losing a baby was normal and something she witnessed every day? It wasn't normal to me, and the hurt was far from any normal hurt that I have ever felt.

### The Effect on my Relationships

My partner went back to work within a few days of me being released from the hospital, and I was left alone trying to cope without falling apart. Losing our daughter put a strain on our relationship. I was angry with him for going back to work so soon. I



mean, how could he just get up, walk out the door, and go to work like nothing happened when clearly, it was hard for me just to open my eyes and face the world every day. My partner going back to work while I was left home alone and falling into a state of depression made me think he didn't care. He kept going on with life, not changing a beat, whereas with me, I wanted to die daily.

I began to emotionally detach from everyone; my partner, my family, and my friends. I didn't want to go anywhere. For months, all I did was sit in what was supposed to be Desiree's room, hold her bear, and cry. I refused to go out because I didn't want to see babies that would remind me of the baby I didn't have. I became isolated from everyone.

### Later Pregnancies

Five years later (2012), I became pregnant again (with my now 9-year-old daughter). My pregnancy this time was monitored weekly. I had a cerclage<sup>1</sup>, was put on bedrest at 15 weeks, and had weekly progesterone shots. As excited as I was to be pregnant, every day I feared that my baby would be taken from me. There was no getting the nursery ready, no buying baby items, nothing. I had to enjoy my pregnancy day by day because if anything would have happened, I didn't want to be left with memories of being pregnant. At thirty-seven weeks gestation, I was taken to the hospital, where an emergency c-section was performed due to the fear that I would develop preeclampsia. About thirty minutes later, my baby girl was delivered. When I heard that "Mommy, I am okay" cry, it was music to my ears. Every day for the first year of my daughter's life, I sadly waited for something to go wrong. Today, I only have my nine-year-old daughter. Many ask, "When the next child will come?" I brush it off as if I don't want any more children,

<sup>1</sup> A cervical cerclage or cervical stitch is a way of preventing the cervix from shortening and opening too early during pregnancy. Doing so can prevent a miscarriage or preterm birth.

but the truth is, I am scared, and I don't want to ever experience the pain of losing another child.

### How I Get Through Life Today

There is never a day that goes by that I do not think about Desiree. There are times when I just smile because I could imagine she and her sister fighting over each other's toys and clothes and one wanting to play while the other one doesn't. The hurt of losing a child never goes away; the pain just gets easier. Today I get through life without Desiree by praying daily for strength, speaking with other parents like me who have experienced the same hurt, by holding my daughter tightly (thinking that if she is always close to me, she will never be taken away), and most importantly, by holding on tightly to Desiree's bear that lets me know that she is still with me.

### Advice for Grieving Parents

*Grieve.* Many of us feel as if we must go on with life pretending that everything is okay after a loss, but please, don't pretend. It's okay to fall apart and not be okay; it's a part of grieving and grieving is a part of healing. There are five steps of grief: denial, anger, bargaining, depression, and acceptance. Allow yourself to experience all five steps. (You don't have to experience them in order, but once you get to acceptance, I promise you will be able to smile and talk about what could have been without breaking down. Please know that there will be good and bad days. On the bad days, reach out to those closest to you and lean on them for support. These are the people who want to help you. Most importantly, I want parents to know that their baby matters. Just because their baby isn't here in the physical world doesn't mean they are less of a parent than those who were blessed to take their babies home. You're a proud parent of an angel baby.

Remember, your baby lived inside of you for a little while but will live in your heart forever . . .



## Caleb's Stillbirth, 5 Years Later

Jill Wieber Lens

**M**y son Caleb should have turned five this summer and started kindergarten in the fall. I was so happy to be pregnant with him. I had two daughters and couldn't wait to meet my first son. I bought so many baby boy clothes for my sweet little guy. So many. I couldn't wait to bring him home from the hospital in his little rocket outfit and hat that said, "Beyond Cute."

We had a doctor's appointment when I was 36 weeks and 6 days pregnant. Everything looked good and we had started to talk about scheduling an induction. I hadn't convinced my husband yet, but I wanted to have labor induced when I was 39 weeks pregnant.

Two days later, on Father's Day 2017, I installed Caleb's car seat to prepare for his birth. That night, I woke up around 11:00 feeling uncomfortable. I walked around a little and went back to sleep. I woke up again around midnight, feeling the same discomfort. I knew something was off, but I wasn't that concerned (certainly not to the extent I should have been). We went to the hospital around 2:00 am because my brother was in town and could watch my daughters.

When the nurses put the monitors on my belly, they couldn't find his heartbeat. I remember them getting more nurses to try. At some point, they stopped trying. But no one said it out loud. I remember when all the nurses later rushed back in when I started screaming, processing the fact that Caleb had died in my belly only weeks before his due date.

Hours later, an ultrasound confirmed what was already obvious. Still though, no one said it out loud. I texted my doctor at 4:00 am that they couldn't find Caleb's heartbeat. Around an hour later, as the on-call doctor finally told us that Caleb had died, my doctor joined us. I was also told that I needed to give birth immediately because I was bleeding internally. (At the time, the doctors thought I had a placental abruption—that my placenta had detached from my uterus, depriving Caleb of oxygen and killing him. I learned about

three years later from a placental specialist that I likely did not have an abruption. Regardless, I was bleeding internally and needed to give birth to Caleb right away).

I was unable to get an epidural because of my internal bleeding. I remember asking my doctor how I was supposed to do this—natural childbirth, which I had never done before, *and* for my dead son. She offered to do a c-section, but I didn't want surgery on top of everything else. My doctor gave me drugs to knock me out.

I don't remember much of Caleb's birth. The pain of the contractions woke me up numerous times. I remember reaching down to try to figure out what was causing me such pain. I didn't need to be there mentally though; my body knew how to give birth.

I woke up later to see my husband holding Caleb. My first words were, "is that our baby"? It was. Caleb Marcus Lens was 5 pounds, 15.8 ounces, and 19 inches long. He was beautiful and looked like a sleeping baby. The only noticeable difference was that his body was not as warm as it should have been. Honestly though, I doubt I would have noticed had I not previously held my daughters right after their births.

\* \* \* \*

Caleb changed everything. I grew up that day in a way no one should have to. I don't know that I'll ever really appreciate the trauma I went through and continue to go through. I'm a different person now. I'm grateful for the person that Caleb made me. But please don't suggest that I should focus on any good that has come out of Caleb's death. And spare me the idea that "everything happens for a reason." Nothing can make Caleb's death justifiable. Nothing can make it okay that he's not here. Nothing can make it okay that I didn't get to celebrate his 5<sup>th</sup> birthday *with* him this summer.

Five years. It's been five years since I held my sweet boy in my arms. So much has changed, but also so little. This essay gives me a chance to evaluate the emotions that I had after his death and still have today (and expect I always will have). It's not surprising to me that the same emotions that were with me after his death are still with me today. They're different, but still present.

The first emotion is love. I love Caleb so. I miss the feel of him in my belly. I miss his kicks and how he used to push his bottom into my ribs. I miss how my daughters used to feel him move in my belly. I especially miss my youngest daughter, then only 2, asking about her baby brother in my belly.

I miss getting to hold him. I'm sure that many would think I'm crazy for wanting to go back to the day of his birth. But I wish I could. I want to hold him again even though he was dead. I want to kiss him again. I wish I could feel him skin-to-skin just one more time. I want to take more pictures of him. I just want more time.

Related closely to that love is my sadness. I am still unbelievably sad that he died just before he was to be born. I'm so sad that I never got to see whether his eyes were blue like his Daddy and oldest sister, or hazel like his other sister and me. Caleb was just an innocent baby and didn't deserve any of this. Neither did his sisters. I am so sad that he is not here chasing them, and that they learned about death so early in their lives. Caleb was about two years younger than my daughter Gretchen, and I will forever believe they would have been the best of friends and such a pair of troublemakers together. But I'll never get to see them together. And Caleb's "Beyond Cute" hat sits on my oldest daughter Hannah's bookcase.

This sadness is not balanced out by the happiness in my life. I have so much to be happy about. I have a wonderful husband. I have my two daughters, and another son born after Caleb. I have a wonderful career, which I have devoted to researching how laws affect stillbirth, all to honor Caleb. I have a great life. But I am still very sad and always will be. Again, the happiness does not cancel or balance out the sadness. It doesn't work like that. Instead, the happiness and sadness coexist; I am both very sad and very happy at the same time.

The same sources of sadness remain sources of anger. I'm not nearly as angry as I was after Caleb's death. The initial anger was closely related to my disbelief. How could this have happened? Why did this happen to us? Not that I want anyone to experience their child's death, but why us? Why couldn't medicine prevent this? Why is the medical

response to stillbirth at term apparently "this happens"? Why did God let this happen? How could God let a little baby die?

I'm still angry. The anger feels more abstract now, maybe also more intangible. Caleb's death is now just simply a part of me, and my anger that he died is simply just a part of me. But the anger is also more specific at times. I am angry that my daughters learned about death so early in their lives. I'm so angry that my daughters pause when asked how many siblings they have. They shouldn't be having to deal with this.

I'm also very angry that in 2022, in the United States, the most developed country in the world, around 24,000 stillborn babies are born each year. And no one seems to care. Other countries are taking measures to try to reduce their (already lower) stillbirth rates. But not so in the United States. Great lengths are taken to prevent the abortion of a 6-week embryo, but very little (if anything) is being done to prevent my fully-developed son's stillbirth at 37 weeks.

I also still feel guilty. Initially, I felt guilty that I had survived his birth, something that wasn't necessarily guaranteed given the extent of my internal bleeding. I felt incredibly guilty that I had taken him for granted—assumed he would be fine. I felt guilty for having moments of happiness, like during a dance party with my daughters. Fortunately, a lot of this initial guilt faded quickly for me. I remember yelling at myself in the car once that I didn't take him for granted any more than anyone else would have at 37 weeks pregnant. I also remember realizing that I didn't have to be sad to honor Caleb. Caleb would want me to be happy with his older sisters; he would want me to sing and dance to Madonna with them. I'm so grateful that I had this realization sooner rather than later.

But in some ways, my guilt has grown. I do not blame myself for Caleb's death. In a support group once, I heard the language that even if my body failed Caleb, that bodily failure was not my choice. That idea has always comforted me.

At the same time, parents are supposed to protect their children. I was the only person who could have known that something was wrong. I'm his mom, yet

my body was the scene of his death. I should have known. I should have protected him. I know that is unfair. I know that there's no way I could have known. But this logic cannot overwhelm the failure I feel as a parent—the failure that I didn't protect him. I don't think that will ever go away.

Another thing that will never go away is being haunted by the possibility that he was in pain when he died inside my womb, the one place he should have been the safest of all. My doctors assure me that he wasn't in pain. I appreciate their reassurances. But they don't know.

I'm a law professor. Once in class, I was listening to a student present about a state law banning abortion at twenty weeks based on the fetus's (alleged) ability to feel pain. Fortunately, the class was remote (during the pandemic) because I lost it. I was 37 weeks pregnant when Caleb died. There's no doubt that he could feel pain. I pray that he didn't. I pray that he died peacefully. I pray that the only thing he felt in his last minutes was my love.

\* \* \* \*

It still hurts when someone tells us we have a beautiful family. I assume it always will hurt. Five years ago, that comment would just take the wind out of me. That still can happen today. But more often, now I'm also able to breathe, smile to myself, and think, "if you only knew." If they only also knew about my beautiful Caleb.



## **I Am a Mother of Three Little Angels**

Indrė Razbadauskaitė Venskė

**I** am a mother of three little angels. My journey of getting pregnant started a while ago. I had different infertility treatments for more than seven years. Finally, after all the challenges and failures, my doctor recommended trying IVF. Two IVF cycles are partially covered by the government in Lithuania. I had to pay for some medicine and a few procedures and check-ups. It was our last hope.

Unfortunately, my first IVF round wasn't successful. Two embryos didn't implant. At that time, I felt devastated, but I didn't know that it was just the beginning of a life-changing trauma. A few months passed, and my husband and I decided to try one more time. After the second round, I received good news "I was pregnant with twins (a girl and a boy)." All these years of trying paid off with a miracle—we were expecting twins!

I was feeling fine. Doctors checked my health regularly. There was nothing I should be worried about. Honestly, we all had "rose-colored" glasses. The "waiting" time was magical. I remember my husband and I were dreaming about both babies' routines—who would do what; how we would handle the napping and washing time at once. Christmas time was completely different, too. We told "the big news" to our parents. We even had our first babies' "gender reveal" party with our closest family members. We also started to purchase clothes, a twin stroller, and other items. But one night, an unimaginable thing happened. It was 2 a.m. My water broke. To be honest, I wanted to believe that everything was fine. It couldn't be that my water broke at 5 months. It just couldn't be! It was my first pregnancy, and maybe I read the signs wrong. I went to the hospital. Doctors asked me to spend the night at the hospital. I was transferred to another one in the early morning.

The diagnosis was a uterus infection. What happened in the days that followed was a massive shock to us. The doctors' council mentioned that there was a chance to rescue the babies (or at least one of them). I got antibiotics, and I felt better. One of the doctors said: "Be grateful for every day because it is a small victory for all of you." Even though it is a cliché phrase, now I understand the actual meaning of it and of life's fragility. I told my babies, "You are fighters! You are so strong. Please stay with me for one more day. God, please give us more time together . . . Please."

One more day passed, and I gave birth at 22 weeks and five days on February 24th and 25th, 2021. My girl was born first and we named her Vilte, which in English means Hope. She was transferred to the NICU. Noah was the fighter. They both were! Doctors wanted me to deliver both babies at once,

but he was persistent. He was still with me for a few hours. I wanted to believe that maybe we would have a “happy ending”—my baby girl was born, and I was still pregnant with my baby boy, who would stay with me longer. I constantly repeated the phrase, “You are a fighter! Please stay with me.” Unfortunately, I lost him during the labor, late on the same night.

I was utterly destroyed, shocked. I couldn’t believe that it had happened to me. I couldn’t see my husband because of COVID-19 regulations, so I was alone with a broken heart. It is hard to describe this feeling. It seems that your dreams and hopes are taken away.

The next day I got a chance to see my husband. I fell into his arms. After that, I didn’t want to think of anything else. Although, I got constantly reminded of the internal chaos and mixed feelings. I always ask myself, “how much can a human being handle”? One moment we can see our baby girl in the incubator and feed her through the mini-medical pipe. Another moment, we have to prepare for Noah’s funeral. In the following days, we were on an emotional roller coaster.

Without my husband’s support, I would probably cry my eyes out. He saw and shared a unique mindset about our baby girl when I thought that life had ended and nothing could bring back the “light” to my life . . . For the last time, we could hold her. We talked with her, and it was a moment where we shared our life lessons. We explained how she should behave, take care of her brother, and “invite us to her wedding” in heaven. I know that it might sound crazy, but at that moment, it was like we had lived through her whole life on earth, and we wanted to give her the best that we had. Our baby girl stayed with us for eight days.

Even though I understand that I can not control everything and consider myself a strong person, these losses affected my relationships, work, and life. I changed. We both did. I noticed that our relationships with friends who are having kids also changed. I am still sensitive to different triggers (e.g., seeing pregnant women and families with twins). I also attended support groups (therapy for women who experienced pregnancy loss), individual treatments, and practiced meditation.

In addition, I prepared a “things-to-do” list for my angels’ memory.

More than seven months passed, and we felt that we were all prepared for one more IVF. Doctors approved, and my blood results showed that we could have a try. After the first round, we were lucky to receive good news—“I was pregnant with our rainbow baby.” I was afraid after the experience of my previous pregnancy, but at the same time, I was so happy that we would have a baby!

I was feeling well, and everything seemed fine until 14 weeks. My doctors checked me regularly, and every time they kept repeating that everything should be okay this time. Then, one evening, I started to bleed. I didn’t have bleeding during my first pregnancy. The bleeding lasted for more than one week. I had antibiotics, but nothing helped. I felt worse every day. I wanted hope and continuously repeated to myself: “Please, not this time . . . Please let us have this baby. Oh, God!”

Unfortunately, I lost my baby at 14 weeks and 5 days on 2022 January 26th. It was a baby boy.

I am trying to be stronger every day. Step by step, I accept the facts and try to see the “light” in the darkest moments. I feel that it is a never-ending cycle. Even though I am 35 years old and have no kids, I am a fighter. I still have hope and believe my little angels support my husband and me in all life decisions.

This story is dedicated to our three angels out there. I share it to inspire and support other families on a long pregnancy journey with life-changing experiences. Stay strong: faith, hope, and love!

“Be grateful for every day because it is a small victory.”



## Finding Peace Through Recurrent Loss

L. Emily Cotter

I had never felt exhausted on so many levels—emotionally, physically, and professionally. It was a year and a half into the Covid pandemic,



and I had been working as a palliative care physician bearing witness to unspeakable suffering and loss. With the more widespread availability of Covid vaccines, my partner and I decided we were ready to try to have another child. Now we were experiencing our second consecutive miscarriage, and the grief felt immense: my uterus cramping and emptied, my heart shocked and devastated, my mind wearied and numb.

It had taken us more than a year to conceive our first child, a young girl who brightened our lives with her smile and infectious joy. Born a few months before the pandemic began, we raised her in an environment we had not envisioned nor hoped for her. Despite what felt like a non-traditional childhood experience, seeing her blossom into a thoughtful human being excited us to think of her one day becoming a big sibling to help love and care for a younger one.

After our first positive pregnancy test, I tried to protect my heart, knowing the prevalence of miscarriages and risks we were facing. No attempt at building defenses could shield from the uncertainty that crept in when the first ultrasound showed a length shorter than expected without convincing cardiac activity. Adding insult to injury, I was sent for a formal (and quite expensive) ultrasound to confirm what my heart knew, and then I waited for another clinic referral to discuss options for miscarriage management.

I recall only a melancholy joy getting pregnant a few months later—the hope and excitement overtaken by anticipation of recurrent heartbreak. This time, cardiac activity on our first ultrasound provided an opening for optimism, although the embryo was again measuring slightly smaller than expected. Trying to put these thoughts out of my head, I continued to live life in the best way I could: being a mother to our toddler and in service as a physician. I focused my energy on a gratitude practice, thankful for my health and the ability to try to become a mother again. Spotting then appeared and intensified, and once again my heart knew this was not meant to be.

While the second miscarriage ended spontaneously, the experience with follow up medical care felt worse than the first. Fellow clinicians provided

unsubstantiated and non-evidence based medical advice about waiting for multiple cycles prior to trying again, despite my age and likely dwindling ovarian reserve. Anger crept in for other patients who would not be able to easily fact-check this falsehood and potentially lose precious time if they, like me, were later in their fertility years. Multiple physicians and nurses projected emotions misaligned with my own, frequently entering the room with a version of “you must be [worried/anxious/nervous]” without an attempt to understand my lived experience. Flippant comments referenced a presumed stress level with an insinuation this was a reason for my pregnancy losses. (While I acknowledge imperfections, I thought I was maintaining a decently well-balanced life raising a thriving toddler despite working as a palliative care provider amid a global pandemic.) I felt disillusioned leaving these medical appointments, embarrassed for my own profession, and alone without medical providers who I could trust to guide me.

I had been candid with friends and loved ones discussing life after our first miscarriage, hoping to break the trend of carrying these losses silently. After the second miscarriage, I found it more difficult to invite people in. I could tell close friends that it occurred, but I didn’t feel ready to grieve openly. I created distance from people who might ask about my pregnancy while simultaneously feeling abandoned by my own body. It seemed my body had failed, with a cruel twist of irony that after a year of struggling to conceive our daughter, here we were, spontaneously getting pregnant yet not making it past the first trimester. I wanted space to grieve alone but didn’t know how to unpack these feelings in moments of protected time when not at work or being a wife or mother. I tucked my grief away, only to have it surprise me in a poem referencing pregnancy loss or after receiving an off-handed comment about having another child.

Since that time, I’ve worked at better sitting with uncertainty, attempting to find peace in living in the moment, and—with the pandemic’s help—a greater appreciation for how little control we have over so many aspects of our lives. I have cultivated even more compassion for patients I speak with in palliative care settings. I acknowledge how incredibly

difficult it can be to find contentment when we have no idea what the future holds, and how beautiful it is to embrace joy in the present moment while letting go of expectations. I strive to avoid presumptions about what someone might feel when experiencing adversity, instead re-committing to greet each encounter with curiosity and generous listening.

We conceived again recently. I allowed myself to hope for the best while taking life one day at a time. I continued a daily gratitude practice: for my health, the health of my family, and the opportunity to hope. And then another ultrasound with interminable silence: scanning, looking, re-measuring without words—the stillness speaking volumes. Perhaps it’s still the newness of it, the shock not yet settling in as the pregnancy hormones remain, yet while the poorly delivered news of my “failed pregnancy” hurt, it did not bring me to my knees. This time I am more intentionally making space for these emotions: fully embracing them as they arise and letting them fill me with the abundant depth of loss. I recall the pain of trying to become pregnant with our first child and honor the opportunity to have conceived with hopes for a different future for our family. I hold in my heart the anguish of those who have experienced infertility and pregnancy loss. I have grown such deep respect for the strength it takes to try again and find peace in accepting a life that may be markedly different from one’s earlier dreams. It may be that our fertility journey is over, or perhaps not. Either way, I will be giving myself grace to embrace the future in whatever way it comes, thankful to have my partner and daughter by my side.



### **Reproductive Trauma: Grief, Acceptance, and a Plea for Grace among Female Physicians**

Giulia Faison

*I*t’s happening again.

I was reviewing some patient charts at the dinner table when I realized I did not feel nauseous

or tired as I had been feeling the past several weeks. A feeling of heavy dread settled over me and sat on my chest, squeezing my heart so tightly that I felt lightheaded. As a physician, and particularly one training in perinatology, I *knew*. I raised from the chair, dragged myself into the car, and drove to the obstetrical triage area in the same hospital where I often went to counsel mothers in recovery after delivering their babies. I waited for several hours, ironically feeling much better physically than I had been. I was walked to a room, where shortly after, an OB resident greeted me while wheeling in an ultrasound machine. My throat clamped shut as I swallowed dryness. *Here we go*. She loudly squirted some cold gel on my abdomen and went right to it. I could not recognize what we were looking at on the screen. I did not see the gestational sac as it should have been. There was no identifiable fetal pole or yolk sac, two anatomical reference marks that should be easily identifiable by now. I just stared at an empty, black circle. The resident said, “So, umm. I’m not sure what we’re looking at. It just looks like schmutz.” *Schmutz? My embryo is now a ball of dirt and debris?! I looked at her blankly. She said, “Maybe all of this will form by next week. I’ll make an appointment with your OB.” I nodded as she was already out the door. I pulled my shirt back over my abdomen gently, as if the gentleness of my movement could revive what I already knew was no longer, and I saw myself out.*

I walked slowly down the brown carpeted corridor leading to the elevators, unaware of the familiar but loathsome “hospital smell” that usually accompanied me on this side of the hospital. I drove home in a daze. I texted my husband once I arrived home and after receiving a response that was incredibly cold and unsupportive—at least that is what it felt like in the moment—I began to cry. One slow and silent tear. As if finally giving myself permission to break, an awful cacophony of sobs erupted, and I felt my heart tear open once again. Vulnerable and alone.

Like many women, I have suffered numerous miscarriages. After the first, those around you seem to think it is easier to bear the subsequent ones since “You’ve been through this before.” Worse, if you have at least one child, as I did, some may even

feel inclined to tell you, "At least you *have* a child," or "At least you know you *can* carry to term," or a whole slew of entirely unhelpful and insensitive comments meant to, I don't know, make you feel better? A loss is a loss. It merits mourning and grieving. To me, life has intrinsic worth. These comments seem to imply that worthiness is quantitative; the more children you have, the less important they become. Equally emotionally and morally useless comments are those that hint that a loss is more meaningful if it occurs later in gestation. A loss is a loss. The value judgment others place on a woman's loss is not just irrelevant; it is painful, harmful, and helps to irrevocably disjoin the person from her surroundings. No bridge exists to connect the two if the gulf of trauma is not supported.

The days that ensued bled into one another in numbness. I was on service and needed to keep it together for the attendings that were scrutinizing each of my actions, the families who relied on my strength and support to help them accept the intensity and uncertainty of the neonatal intensive care experience, and the babies whose premature little bodies struggled to cope with life outside the womb. I wore darker eyeliner than usual to cover my swollen, red-rimmed lids from the tears that eventually dried up into fragmented sleep. I wore concealer and blush to hide the dark circles beneath my eyes and give my complexion the appearance of a happy and confident fellow. Somehow, I completed rounds with smiles and jokes, while inside I felt transparent and hollow. My OB appointment finally came. A repeat ultrasound confirmed what I already knew. The OB, not my primary doctor, said, "I'm so sorry. You *will* conceive again." It was literally the *last* thing I wanted or needed to hear. Certainly, looking back, in any other circumstance with me *not* being the patient, I would have thought those words were expressing empathy and hope. But in that moment, I thought: why is she sorry? What does that have to do with losing a baby? How is that even helpful? Why would I want to conceive again, when I just lost a life? What about the life I just lost? What about the baby that is dead inside my body? Did it suffer? Does it still feel me? I so much wanted to hug it, have it feel my warmth and love, be its mom. Did it know it was inside of its

mommy? Did it feel loved in the 10 weeks and 2 days that it was living? I felt so incredibly helpless and useless. What kind of mother is not there for her child when it dies? I nodded in her direction. She just stood there and stared at me. So I tried to smile, but felt the tears coming. "It will be ok," she said.

Again. Not helpful.

*No it won't. This life will never come back. Stop trying to comfort me.*

The following week I went in for my D&C, the surgical removal of the implanted embryo. It was all familiar, having been through this before; the quiet movement of the nursing staff around me; my husband holding my hand; the anesthesiologist asking me to count backward from ten; the last glances of the same operating room I had been to before.

I woke up to my husband talking to my OB about how much I wanted to have a baby. I couldn't open my eyes. I was in and out. I did not want to wake up. I wanted to sleep forever.

The following day I was off service and starting vacation. We drove to San Diego and stayed in a rental we found months prior. I stared out the window without a word for the two and a half hour drive while my husband hummed to a song on the radio. *How can he hum right now? Why isn't he sad? Why isn't anyone else sad?* Tears welled up and fell down my face. I tried to tune him out. I looked at the sky and the birds, and the ocean in the distance. *I just want to be air. Air does not feel anything. Air is weightless. I want to be air.* Day #1. The first day without my baby.

Then it was the second day without my baby. And then the third. And eventually the first month, second month, third month. And eventually my baby's due date. Every moment in time was tied to the life that had been lost. I imagined what he or she would have been like at two months, if he or she would be rolling at four months, etc. It has been two years now, and I still think about the person that could have been. Even amidst the blessings of having other children. Thankfully, this was the last loss I experienced.

My first loss had occurred five years prior. I was not feeling well that day with an excruciating headache and was in the midst of examining a two-month-old infant in my outpatient practice. He



was very small for his age and I asked his mother how he was breastfeeding and how she felt about his growth. As she began to answer, I felt a warm sensation trickle down my leg. I quickly excused myself and walked to the restroom. Blood was dribbling down my leg. Our office bathroom was thankfully stocked with feminine products, so I was saved in that regard. It was not until I returned to my patient's room that I realized I was probably miscarrying. I must have dazed off while the mother explained all of her breastfeeding strategies because when I finally looked at her, she was glaring at me with frustration. "So?" I looked back at her and said I thought she needed to start some formula supplementation after each breastfeeding session to help her baby's weight increase. Once we consistently achieved a healthy weight gain, we could back down on the formula. Her nostrils flared in anger as she said, "Didn't you hear what I said? All of my other babies were called 'failure to thrive' and they're all fine." She picked up her baby and stormed out. I stared at her back, paralyzed in dismay at her reaction.

Later that afternoon, my boss knocked on my office door. She received a poor review on yelp complaining about my lack of empathy and poor listening skills and that I had no bedside manner whatsoever. My boss said, "I know that's the exact opposite of who you are. Are you ok?" I burst into tears. She told me to go home. Of course, as physicians, our training brands us with a work ethic that surmounts all else. I completed my notes, now hunched over with cramps. I mean, how was I going to complete my notes after my miscarriage? I immensely hated that mother in that moment for her own lack of empathy. I hated her for not having a job, which provided her the *luxury* of time to complain about her pediatrician. Of course, I also hated her for having a cute little baby. And then, I hated myself for having these thoughts, which would continue in the subsequent months as I saw healthy babies and pregnant mothers—inescapable reminders of the unattainable, the absent. Small insults would prick and prod at my wound, causing me to linger in my depression and anger. But, this was the first wound, the quickest to heal, surrounded by healthy and vital tissue.

Several years later, after many discussions with my husband, we saw a reproductive endocrinologist. Now that I have completed my reproductive journey, the grief and bereavement of what will never be holds hands with the joy and contentment of what is. I have a full heart and can confidently say that I am ok with experiencing emotions as they come.

Despite the depersonalization I felt through each stage of loss, opening up about my experiences with other women has allowed me to find some solace through connection. All women have a reproductive narrative. We are united by our biology, whether we choose to utilize it or not. And women physicians, in particular, must stick together. I don't know who it was that first advised, "You can't take care of others unless you take care of yourself," but what if your job *is* to take care of others?

We take care of pregnant women, women who cannot or do not want to be pregnant, we take care of healthy babies, babies that die, and families torn apart by different values regarding conception, loss, and bereavement. We do not have the luxury of sitting with grief and looking at it eye-to-eye. Physician women, and more specifically, physician mothers, are in a uniquely challenging position whereby their suffering necessarily becomes suffused beneath the role of the caregiver. Their ability to cope, heal, and ultimately reconceptualize negative experiences becomes stunted, and at times even severed. So, at the very least, we must be kind to each other and have grace with one another. To the resident that called my embryo "schmutz," this includes you.



## A "Good" Patient

Erica C. Kaye

**A**ll I wanted was to be a mother. The yearning was an animal thing, instinctive and unconstrained, fierce and precarious. Everything else became surrounding noise. Each day, I went

through the motions; but in a parallel world, fragile hope cyclically fractured, again and again.

I've struggled with infertility and pregnancy loss for as long as I've been a doctor. Most memories from my medical training and career are tethered to the pain of childlessness. On 24-hour shifts, I hid in an empty parent room in the pediatric intensive care unit, injecting hormones into my knotted backside. Three hours after transferring a fragmenting embryo into my inhospitable, cramping uterus, I led a memorial service at the hospital for children who died. I received the call that I was not pregnant while sitting on a crowded city bus on my way to staff a resident clinic, tears streaming down my face.

A decade later, the memories are still raw. Like visceral imprints, they silhouette and contour my sense of self. Across my training, so many people told me who I was "supposed to be." A dedicated clinician, dependable colleague, erudite researcher, thoughtful educator, devoted mentor. I tried hard to meet everyone's expectations, but I was compressed by misery. In my guts, I knew that what I was supposed to be was a mom.

Anxiously, I sought out fertility treatment. As a physician, I thought I was prepared to navigate the healthcare system as a patient. In retrospect, I was brutally naïve and inexperienced. I was training to become a pediatric palliative care physician, and I saw the practice of medicine as a pathway towards holistic care for a person's physical, emotional, spiritual, and social wellbeing. I was learning to ask patients about their goals, values, hopes, fears. To see the whole patient and wonder about their personhood. To prioritize their dignity and humanity.

When I entered the fertility healthcare system, I was disoriented and scared. The clinic was a cold, sterile space. When I felt invisible, I blamed myself for not being savvy enough to navigate the system. I think a part of me believed that, if I was a "good" patient, someone in the system would see me and care.

It was strange to be wholly unseen, and yet completely, grossly exposed. Infertility stripped me bare—bodily, mentally, financially, existentially. I was systematically surveyed for defects, my failings interrogated, the broken parts scrutinized. Problems

without a straightforward fix were discarded. Healthcare professionals calculated the sum of my deficits with ease, but no one noticed a person drowning in grief.

Medical training conditioned me to take up as little space as possible, to apologize for the inconvenience that my issues or worries might cause for others. The fertility clinic made repeated mistakes: incorrect prescriptions, instructions that didn't make sense, communication breakdowns. But I was too overwhelmed to question or examine things closely, and I was incapacitated by isolation. My husband, also in medical training, was living in another state. We had not told anyone about our infertility struggles, and I shouldered the weight of navigating my medical care alone.

It's hard to think back to those days. Grief was a physical hole in my chest, sucking out air. I didn't know how to function, to be whole again. Anguish born from invisible, intangible loss is intense and alienating. I felt guilty about my degree of suffering when I lacked visible scars to justify the wound. Practically, I didn't have the emotional bandwidth to explore or tend to my grief; I was too overwhelmed and drained by the stamina needed to steer through a disinterested, chaotic healthcare system.

After residency, I joined my husband in another state. We were devastated to learn that, in crossing state lines, we had lost our fertility coverage. We found a new clinic in the area and began draining our hope and savings. Across two subspecialty fellowships and an early faculty career, we did multiple IVF cycles and mourned the loss of five desperately wanted pregnancies. It was the darkest time in my life.

As hard as it was for me to face my grief, it was harder to interface with the careless trauma of the fertility clinic. Staff casually congratulated me during a miscarriage. Technicians brusquely entered the room and inserted a vaginal probe without introducing themselves or making eye contact. Nurses miscommunicated directions, then blamed me for their errors. I lost count of the number of times that no one called me back, incorrect directions were given, the medication was not called in, the requisite supplies not ordered.

As a fertility patient, I learned quickly that I was invisible if I stayed quiet and “difficult” if I spoke up. When errors occurred, I found myself apologizing repeatedly for requesting clarification, as if things were my fault. On a subliminal level, I knew my tenuous place in the hierarchy, and how quickly the system could knock me down.

The healthcare system has a long and storied history of demeaning and discrediting women. I’ve seen and lived it from both sides, as a doctor and as a patient. Although I am trained and board-certified in hematology, I internally debated for days whether to question an anticoagulation plan that I knew was pharmacokinetically inappropriate. When I finally mustered courage to request a different anticoagulation plan, I was chastised defensively by my male hematologist and accused of being “difficult” and “litigious” by my male fertility doctor.

Women who present with physical and emotional ailments are habitually ignored or disparaged by healthcare professionals. Infertility is a clinical space between Scylla and Charybdis—a physical ailment that begets profound psychological, spiritual, and socioeconomic suffering, yet receives little holistic attention or compassionate ministry.

It wasn’t until I joined a private online community of women physicians with infertility that I began to grow self-awareness and find strength in solidarity. I was stunned to realize that many women physicians had experiences very similar to my own. I read story after story about women being disregarded or labeled as “difficult” during their infertility treatment. I saw familiar examples of the healthcare system routinely undermining our credibility, minimizing our suffering, and gaslighting our lived experiences. I felt sick, absorbing these stories. But I also felt seen for the first time.

In a profound way, connecting with other women physicians with infertility helped me reconnect with my own goals, values, hopes, and fears. I saw my own humanity reflected back in the stories of strangers. Through their bravery and resilience, I relearned how to prioritize my dignity. Their messages of compassion and strength also empowered me to activate my voice. I stopped trying to curate

the image of a “good” patient. I no longer felt compelled to be quiet and convenient; I wanted to advocate for myself, and for others.

After months of reflection, I wrote a letter to my fertility clinic, asking them to consider several strategies to minimize errors and miscommunication for future patients. I explained that my goal in sharing feedback was not punitive; my hope was that thoughtful changes could help improve care for patients and families. The letter cemented my reputation as a “difficult” patient, but I didn’t regret my decision. After years of frightened silence and disempowerment, I was grateful for my newfound voice.

Through IVF, we were so lucky to welcome our daughter after a difficult pregnancy where we grieved the loss of her identical twin. Several years later, I again became pregnant through IVF, but I developed a blood clot in my leg, and we lost the pregnancy. I underwent extensive testing that showed no underlying predisposition for clotting, and my hematologist determined that my clotting risk was no higher than the general population. The clot resolved with medical management, and multiple specialists recommended that it was safe for me to proceed with IVF again.

But my heart and spirit needed a break. We adopted our younger daughter through open adoption the following year, and she brought our family joy that we couldn’t have imagined. I healed, and as she grew and thrived, I felt ready to try again. We did two IVF cycles and froze untested embryos, hoping for me to carry them. But in further conversations with my husband, he vulnerably shared his anxiety about the unpredictability of pregnancy, and we ultimately decided to use a gestational carrier. We grieved and felt terrible guilt when our gestational carrier experienced a miscarriage with our first untested embryo. We decided to do another IVF cycle with genetic testing in the hopes of creating a genetically normal embryo for our gestational carrier.

My fertility doctor performed an exploratory laparoscopy on me before doing another round of IVF, as I had increasing symptoms of endometriosis. A few months later, I started oral contraceptives to begin the cycle. We purchased thousands of dollars

of medications prescribed by the fertility doctor. But on the 10<sup>th</sup> day, I was blindsided by a call from the doctor, who offhandedly informed me that the partners in his practice had met without him and voted to abort my cycle and fire me as a patient. I was stunned and completely confused. When I asked for an explanation, he said that the clinic had decided that my risk for having a future blood clot by taking the fertility medications outweighed the potential value of me trying to grow my family. Thus, they unilaterally terminated my cycle mid-way and removed me as a patient from the clinic, without any discussion with me.

I felt shocked and powerless. I struggled to understand how the clinic's values (avoiding potential for a theoretical medical risk) could irrefutably trump my values (a deep desire to have another child). I reminded the fertility doctor that multiple specialists had cleared me for IVF. That my risk for clotting was no higher than the general population. That their clinic routinely treated patients with clotting disorders, all of whom had higher risks than me. That in the 4 years since the clot resolved, I had paid out of pocket for two IVF cycles with their clinic, neither of which they cancelled. That the fertility doctor had recently performed abdominal surgery on me, specifically in anticipation of doing future IVF cycles. I requested to speak directly with the partners who voted to cancel the cycle, and they refused to talk with me unless I paid for a consultation the following month.

The sudden abandonment was bewildering. I was stunned that a group of doctors who had never taken my medical history, never personally evaluated me, never discussed my risks, never explored my hopes or goals could, without warning or explanation, abort my cycle mid-way and fire me as a patient. In this moment, I felt myself fully wake up. I knew that their claim of "risk" was medically unsubstantiated. I saw, with clarity, how they projected a value judgment of who I was supposed to be and how "it wasn't worth it" for me to grow my family. The brutal truth was that I wasn't worth it to them.

Wrecked, I turned again to the forum of women physicians for wisdom. There, I found comfort in

a community whose stories were mine, and theirs. Shoulder to shoulder, they stood beside me, sharing similar stories of pain and solidarity. The most meaningful message came from a woman who wrote simply: "You deserve to be treated with respect. You deserve full honesty and openness. You deserve kindness and compassion."

Infertility steals so much from us. Our joy, spontaneity, self-worth, dignity. My experience as a fertility patient deeply eroded my confidence and sense of self. But a decade later, I'm genuinely grateful to walk away with a clear, unflappable understanding of what I, and all women struggling with infertility, deserve. Empathy. Respect. Dignity. To be seen, in all our humanity.



## Thrice the Pain

Taylor McIntyre

Like most girls do, I grew up dreaming about becoming a mom, baby names, pregnancy, and starting my own family with a handsome man. Well, that day came a little bit sooner than expected. I was a 19-year-old college freshman when I took my first-ever pregnancy test. I about fell over when I saw those two pink lines, and boy was I scared—scared to tell my boyfriend and parents; scared about how a baby would change everything about my education and career path; scared about how it would affect my friendships. But mostly, I was excited. I was the oldest of 4 kids and had helped raise my three younger brothers. I could do this! A baby of my own would be magical!

I told my boyfriend, and while he shed a few tears out of fear, he was excited too, and we decided to get married! While initially shocked and a bit disappointed in my actions, my parents got past that and were already looking forward to their first grandchild. With all that out of the way, the next stop was our first doctors appointment! I was 9-weeks by the time I got in, and I was so thrilled to

check on my tiny babe. After all the normal exams that get pretty personal, it was time to use the doppler to check on the heartbeat! The doctor looked and looked all over my belly, but the only heartbeat we could hear was my own. This scared me but the doctor assured me that it was still early and there was no reason to be alarmed; we'd hear it next time. So I tried not to worry and went on with life. I spent most nights dreaming of my baby and most every day planning our future. At 13 weeks, I went back to my OBGYN for our next appointment, and of course I couldn't wait to hear that heartbeat finally. Once again, no dice. No matter how long he searched, he could not find the heartbeat. I thought for sure we would do an ultrasound to check everything out, but no—the doctor said that sometimes based on the location of the placenta and other variables, it could just be difficult to hear, and we'd for sure hear it next time. I was so young. I just didn't know enough to recognize that something was really wrong. I tried to lock away my anxiety and looked forward to the next appointment because I knew at that point we'd be getting close to halfway through and finding out the gender of our sweet baby.

While we'd already sent out invitations for the wedding, I was 15 weeks and 6 days pregnant when my boyfriend got down on one knee with a ring and officially proposed! It was such a special night until I felt a gush of fluid suddenly run down my legs. What in the world?! Honestly, I thought I might have peed my pants. We laughed and I headed to the bathroom to check it out. I was a bit surprised to find a thick, yolk, yellow fluid in my pants. I freaked out and we headed straight to the emergency room. I suffer from pretty severe anxiety. My teeth chattered and I shook the whole way there. They tested the fluid to see if it was amniotic fluid and it wasn't. They told me they were going to do an ultrasound. They hid the screen from me during the exam and told me that a doctor would be in to tell me the results. A female doctor came in with heart-breaking news. She told me that my pregnancy was a blighted ovum. I struggled to understand what she was saying as I tried to internally process that I wasn't going to be having my baby. She said that my body had tricked itself into growing an empty

yolk sac and that it had actually stopped growing around 11.5 weeks. Now my body was going to go through the process of expelling all of that from my uterus. I had had a miscarriage. I was in shock and before I knew it, a nurse was coming in to help me get cleaned up and discharged from the ER. I'll never forget the cruel words that came out of that woman's mouth. She said, "Well, at least it wasn't a real baby." Wasn't a real baby?! I don't care about semantics. I had just spent three months knowing that I was pregnant and planning this child's whole life! She (or he) would be so tiny at Halloween. What costume would I dress her in? Planning the nursery, baby names, first Christmas, where we'd live, where she'd go to school. That baby was beyond real to me, and I was infuriated that the nurse would say any different. And I was especially infuriated at my doctor because if he had given me an ultrasound when they couldn't find the heartbeat, I could have known weeks or even months ago. My boyfriend cried all night. I just lay there in shock.

I went to my OBGYN for the follow-up and he assured me that just because this happened, it didn't mean anything was wrong with me, nor did it mean I was any more likely to experience another miscarriage in the future. They tried their best to prepare me for what my body was about to go through and sent me on my way with instructions to keep the tissue I passed so that they could run tests on it. They told me to follow back up in two weeks. The next day, my fiancé and I left for our nearly 2-hour ride back to our college town, and that's when it hit. Let me tell you; you don't want to be in labor in a small single cab pickup. It was miserable. I say "in labor" because I really was. I was having contractions every few minutes. We had to stop at gas stations in multiple towns for me to just sit on the toilet and cry for 20 minutes at a time. I had never experienced pain like that in my life up to that point. Eventually, we made it home and things calmed down. I tried to collect what I could into a water bottle and put it in the freezer but it seemed that all there was were clots. That weekend I went wedding dress shopping in the city with my mom and aunts. In the middle of trying on dresses, I went to the bathroom and that's



when it happened. Sitting there in the toilet was a round ball of tissue that was the size of a golf ball or larger. I suppose it passed from my cervix the day I was having contractions but had just been sitting in my vaginal canal since then. It was rough, and it brought a lot of emotions back up in the middle of what was supposed to be a huge day in my life. I flushed it down the toilet. There was no way to save it at that moment and I didn't want all of my family to see it. I had to move on.

Our wedding day came and went, and really all I could think about at that point was how badly I needed a baby. One month into our marriage, I found out I was pregnant again! I was ecstatic and so was he. I knew that I needed a new doctor this time and happened to find one who gave ultrasounds at every single appointment. It was just what I needed to ease my worried heart! I went in at about 8-weeks and there on the screen was a tiny little baby moving around and a heartbeat! I remember asking the doctor, "Is that real!" I just couldn't believe that baby was actually alive inside me! We waited until the first trimester was over to announce, and of course everyone was thrilled for us. We found out that he was a boy right around the due date of my first pregnancy. It helped ease that pain, knowing that I had a baby coming! I went on to have a very healthy little boy, born at nearly 40 weeks. It was the best day of my life, and I knew that all the sadness and loss were behind us.

I always knew I wanted my kids close in age, so we weren't too careful to prevent pregnancy at that point. When our son was 9-months old, I took a pregnancy test after being late for my period, and it was positive! I was so excited and went ahead and scheduled my first prenatal appointment for 8-weeks. Unfortunately, just a week or two later, at less than 6-weeks, I began bleeding. I knew I didn't want the trauma of going to the emergency room again, so I waited until the next morning and called my doctor. They got me in right away. The doctor gave me a vaginal ultrasound and immediately said, "I'm sorry Taylor, this isn't a good one." While the blood had prepared me, that was still crushing to hear. Since my cervix was open, my doctor had a vacuum-type machine and cleaned me out right then and there. Now it was time to heal again. Once

again, this child and life you planned for are just gone. I was so excited about my kids being so close in age. I literally didn't even know what to do. I was distraught, and while I desperately wanted another baby and to immediately get pregnant again, the fear of going through another loss made me pause. I wasn't ready for that. I told my husband that I didn't want to talk about it. I didn't want to think about it either, but of course I did. Talking about it out loud made it more real—it was easier to pretend it didn't happen.

A few months later, I just couldn't wait anymore. My son was over a year old, and like I said, I wanted them close in age. I got pregnant the first month of trying and we were ecstatic. Because of my history of loss, my doctor let me come in as soon as I had a positive test. I went straight to the doctor and unfortunately, it was too early to really tell anything. We couldn't even detect a heartbeat yet. He assured me that this wasn't abnormal this early and had me come back in two weeks. At that point, I was a little over 6-weeks pregnant and there was a heartbeat! Oh, I felt so much relief! But due to two miscarriages in my past, we were very careful to keep it quiet, just in case. My next appointment was at 10.5 weeks and I couldn't wait to see that baby again! My doctor started the ultrasound and there was my sweet baby on the screen. We all stared at the screen while he moved the probe around and I could tell something was wrong. I'd been through this a time or two and knew we should be seeing a flickering heartbeat but it was there. My doctor was very kind and apologetic. He knew our struggles and he hated to give us this bad news. My baby was dead. He or she had stopped growing around 7.5-weeks, three weeks prior to this appointment. Because it had been a while and my body was showing no signs of miscarrying on its own, he told me that I would need a D&C, and we'd have to schedule it with the hospital.

Remember, I mentioned my anxiety earlier on? Well, when he mentioned a medical procedure at the hospital that I would have to be put to sleep for, I immediately started panicking. My doctor knew me and cared about me. He decided that he could take care of it in his office if I came back the next day. I did, and honestly, I had no clue what was about to

happen to me. The best way I know how to describe it was that he gave me an abortion. He injected some pain medication into a vein in my arm, but I really don't think it worked. He somehow opened my cervix and inserted what I can only describe as a giant needle. He then just stabbed away, chopping up everything in my uterus, including my sweet baby and then sucked it all out. Not only was it painful, but it was pretty traumatic for me. It's hard to think about. I have a lot of regret. But now, it was time to heal again. He told me to come back in 4 weeks to check everything out. This miscarriage might have been the toughest on me. It was the second one in that year, and seeing the healthy baby early on allowed me to get my hopes up a little bit. I did not know if I could do it again. How could I? It really put a lot of stress on my marriage. Not only was I broken emotionally, but the hormones were awful. I felt like I was always up and down. I had spent so much of the last two years pregnant, postpartum, or post-miscarriage. It is very rough on your body. But I had to push through. I had a little boy and husband who needed me. I remember telling my husband that when we hit 5 miscarriages, I would be done forever. I just knew that I was never going to get another baby, but I wasn't done trying. I went to my follow-up appointment and my doctor did an ultrasound just to make sure that everything was okay. He was able to see and tell me that I was ovulating and that if we were ready, we could start trying again that day. While we didn't know the cause of all my miscarriages, we knew that while I could get pregnant very easily, I just had a hard time staying pregnant. My OB suggested that I take 4 times the normal dose of folic acid, starting immediately. Maybe that would help.

Well, you guessed it. A few weeks later, I had a positive pregnancy test! Was I excited or was I terrified? I honestly couldn't tell you. A little bit of both, I guess. I refused to get my hopes up. I really didn't even let myself think about it because then maybe it wouldn't hurt so bad if I lost it. As usual, I went to the doctor right away, and once again, there was a heartbeat! I knew from experience that this didn't mean I was going to get another baby though, so I still tried not to think about it too much. Four weeks later, I went to the next appointment and once again

saw a healthy baby wiggling around. I just knew this was going to be my "take-home baby." We went on to have another full-term, healthy son! I never thought the day would come, but it did, and it was incredible.

My marriage didn't survive, but I went on to marry again and had a 3rd healthy son (my big boys were 6 and 4 at the time) with no more losses. Once again, I took the extra folic acid, and he was just fine. Oh happy day! I later took a genetic test that measured how my body metabolized certain medications, and low and behold, I have a gene mutation that doesn't allow my body to produce or metabolize folic acid normally, so that might have really made a difference!

My losses were hard. So hard. But while you never forget the pain, the pain does get easier. For me, what made it the easiest was realizing that if I had been able to carry my losses full term, I literally wouldn't have had the babies that God gave me to raise and love. I know that my three sons were meant to be mine. I also named all of my miscarried children. I felt like it made them more real. Their names are Hayden, Colby, and Sawyer, and I will never forget the days I carried them inside my body and longed to hold them. I have advised other suffering mothers to do the same. I truly feel like it helps. I have a lot of faith that I will see them one day, when my time comes, and I look forward to that so much. While emotionally, I wasn't able to talk about it through those hard years, I now enjoy talking with other moms who have suffered losses and always encourage them never to give up hope and keep trying. I'm so thankful that I did.



## Gravida Plus One

Anita Kumar Chang

**T**he moment I found out I was pregnant was also the moment I realized I was likely having a miscarriage. A week after that first pregnancy test, I found myself lying on an

exam table at the obstetrician's office, undergoing an ultrasound to try to confirm the pregnancy or lack thereof. I lay quietly as the doctor pushed the probe around, searching and searching. I watched my husband's face as he watched the ultrasound screen, knowing that he, an emergency medicine physician, would understand what was happening before the OB told me. I could see concern, but I couldn't decipher more than that. I waited.

After what seemed like an hour, the doctor told me, matter-of-factly, "yeah, there are no products of conception in the uterus," then turned and walked out of the room. I was stunned into silence. How could this be the way I found out? It was shocking and anti-climactic at the same time. As a physician myself, I was acutely aware of the lack of bedside manner and the lack of humanity he showed me. This may be a routine result for him, and he was certainly acting like it, but for me, a person who'd been trying to conceive for years, it was shattering.

I don't think I started to cry until we reached the car. My husband and I sat there in silence as I wept. He was in his usual mode for dealing with bad news, denial. From the moment I took the pregnancy test until now, he hadn't had much hope, so he had prepared himself against being disappointed. I had known from the first spotting that my chances were 50/50 of miscarrying. But I like to read into things. I had calculated from my last menstrual when I must have conceived and realized it was on our wedding anniversary. It felt like a sign that this was meant to be and it was going to work out in the end. I had just moved to a new town to start my first job since finishing training. With all the "new," a new life coming into the world seemed to make sense. Yet, it wasn't happening.

The stress didn't end there. The day before I flew to Savannah for my girlfriend's bachelorette party weekend, I had to have my blood drawn to track the pregnancy hormone to make sure it was trending downward appropriately. As I was waiting for my luggage in baggage claim, I got a call from the OB's office. My lab results had come back and it wasn't looking good. They wanted me to go directly to the nearest emergency department to make sure I wasn't having an ectopic pregnancy, a potentially life-threatening condition. Now in crisis-mode, my

friends at my side, I went to the nearest ED and checked in. Part of the workup was another ultrasound, this time done by a technician in the radiology department. While transport had wheeled me to the ultrasound room, no one was there to pick me up after the test. I waited in a wheelchair in the hallway for a while. Then the ultrasound tech, noticing that I was still waiting, gave me a pat on my back and with kindness, wheeled me back to the ED. It's strange how, at times like this, the smallest show of compassion makes its way deep into one's memory. The results came back, it wasn't ectopic, and I passed the products of conception.

Back in my new hometown, the next week, I went to see the midwife I was originally scheduled to see for my first pregnancy appointment. I felt my face flush as I filled out the forms in the waiting room. What surprised, disturbed, and upset me, was the realization that I would forever be marked in OB notation as having had a miscarriage. In medical school, we learn about how to introduce a patient's obstetric history. The most basic part is the 'gravida para' numbers; gravida for the number of pregnancies and para for the number of live births. I was now G1P0. No matter what the future held, my gravida number would always be one higher than my para—if I was even able to have children. I grieved the pregnancy and the potential for the future with that realization.

The visit with the midwife, however, alleviated much of my distress. I remember immediately feeling the warmth and empathy as she entered the room. She asked if a student could be in the room for the visit and then began to talk to me about miscarriage. She acknowledged the loss and told me it was okay to be upset. It was a loss like any other loss in life, a loss that warrants grief. She told me how common miscarriages are and how much more often we know about them now due to earlier detection of pregnancies. She normalized the experience and told me it wasn't my fault. That last part was the part I needed to hear most. Since the process began, I wondered if it was my fault that the pregnancy failed. Was it because I had been too stressed out during the end of my training? Was it because I hadn't been eating healthily enough? Her reassurance meant the world to me.

After this visit, I was able to work through the grief of what I had lost. It was a strange loss, unlike most losses of loved ones in life. Since I had never met my baby, a baby that had never even really formed, I wasn't sure how much I was 'allowed' to grieve. I typically process things by talking with people, but now I was surrounded by people I wasn't sure I wanted to talk about this loss with. When I began work at my new job, I mentioned that I had recently had a miscarriage. I was frequently met with discomfort and averted eyes. However, many women shared with me their experiences of pregnancy loss. Hearing these stories, I began to feel hopeful again despite the fear that this would be the way it would always go.

When I became pregnant several months later, I felt like I was constantly holding my breath. Every trip to the bathroom was hounded by fear of seeing spotting again. As time went by and the pregnancy proceeded, I was able to start to believe that this time it would be okay and I was able to enjoy being pregnant. As with all grief, time helped.

Three and a half years later, I have two children that I was able to conceive and bring to term. I think about that pregnancy that I lost. The way I've come to think about it is that that baby wasn't ready to come into this world yet. So many things have to line up for a baby to come to term, and they simply didn't that time. It wasn't my baby's time. But time passed, and my babies came to me at last. As a G3P2, I still carry the loss with me, but as with all losses, it's only part of the story.



### **My Three Pregnancy Losses: A Story Told From an OBGYN Physician Working in Japan**

Shizuko Takahashi

**W**hile I have been a practicing Obstetrician in Japan for over twenty years, the biggest lessons I've learned have been through my own pregnancies, the first three of

which ended in miscarriages. Prior to these losses, I was unaware of just how little comfort the scientific explanations provided patients who were struggling to fulfill the socio-cultural norms that accompany carrying a pregnancy to term. Each time I treat a patient who is miscarrying, I reflect on my own experience, and reassure them that the body will heal more quickly than the mind (or spirit) and that they shouldn't blame themselves.

I was married, late for a Japanese woman (36 years old), to a man whose father had survived the atomic bombing of Hiroshima. At the time of our marriage, my mother-in-law spoke of her concerns about our ability to have children due to both my age and possible latent radiation damage in my husband. After a year of trying to conceive, I discovered I was pregnant right after one of my patients happily told me, "I will share my pregnancy germ with you." My hands shook with excitement as I held the positive test result.

At the peak of my career as an OBGYN practicing in Tokyo, working nights performing emergency C-sections, endoscopies, and open surgeries, I was determined not to let my own pregnancy get in the way. A colleague confirmed that the gestational sac (a cavity surrounding the embryo) was in my uterus via ultrasound and I notified my partner. We were thrilled. The world immediately looked different, especially children. My partner seemed especially happy to be finally a father at almost 50. My mother-in-law and my parents were excited to finally become grandparents. However, happiness only lasted one week. During my night shift, I started cramping and bleeding. My colleague offered to examine me, but I did it myself. The (gestational) sac was heading towards my cervix, I knew that I was having a miscarriage. Within hours, dilation and curettage (D&C) was done by a colleague and I was discharged from my own hospital.

Until then, I had never had surgery or been on any anesthetics, so everything felt unreal. I was now a patient and my boss was telling my partner over the phone the same things that I would say to a patient who was miscarrying. "The surgery went well." "Miscarriage happens in 30% of pregnancies for a woman her age, caused by the lack of viability of the embryo itself." "She is not to blame."

My partner picked me up that afternoon and I was to take that weekend off. He said, "We can try again. It is my bad luck. Everything I do the first time ends in failure, like my first marriage." I was not relieved by my partner's kind words. While he wanted to move on from that experience, I was stuck. To make the best out of my weekend off, we went out to one of the fanciest restaurants in town, but I couldn't taste anything. All I wanted to do was grieve quietly, in the comfort of my own home, but my partner wanted to move on. After the weekend, it was not just my partner but my work and family trying to move on as well. My mother-in-law advised me to prepare myself "better for the baby, to become a better mother." This meant not working full-time—and treating only out-patients (mostly sitting), eating food and wearing clothing believed to keep the body warm for the baby, etc. Several months later, I made the sacrifice and became a part-time physician.

Avoidance was my partner's way of dealing with our loss, so I felt isolated. But we tried again and 6 months later, I was pregnant for the second time. This time, we decided to keep it to ourselves until we could confirm a heartbeat. I became paranoid about the life inside of me and looked under the ultrasound every day, nervous that I would miscarry again. I did everything possible to keep the baby. Gladly, I confirmed a heartbeat at 8 weeks. Just as we felt safe to start disclosing people, the heartbeat stopped at 10 weeks. As I looked at my fetus inside a small glass container, my partner said, "I am not vulnerable this time, I stopped expecting anything. You know this might happen to anyone; you are an OBGYN after all." I asked him to take a picture of me with my baby in the glass container. I was trying to tell him that I didn't want to forget and I didn't want to move on. Strangely, as he took a photo, I tried to smile as much as I could. I thought it was the only way to show gratitude towards a life that came to me even temporarily.

As an OBGYN, I have always wanted to experience pregnancy and delivery for myself. Now, in my late 30s and with my biological clock ticking, I had to convince my hesitant partner to go through IVF to stock up on embryos as "mental insurance"

in carrying a baby to term. To my surprise, he was against IVF, because it was so "unnatural." He told me that he wasn't "that desperate and we could just live without children if that is fate." I told him it may be too late if he feels "desperate" in the future. My mother-in-law helped convince my partner, as she somehow felt that surviving an atomic blast had some kind of influence on my two consecutive miscarriages. As my mother-in-law was orphaned by the Hiroshima a-bomb, she was resistant to change. "You don't have to go the natural way," she said to us. "Once the baby is born, who cares how it was conceived!"

With a promise that we would wait until I was at least in my forties to transfer them, my partner agreed. We made two embryos to store. Even with the two embryos in storage, I was unable to overwrite the two lost lives (miscarriages). While everyone else thought I carried on very well, my knowledge as an OBGYN made it impossible for me to ask for help. Finally, I asked my partner to have a Buddhist ritual called "Mizuko-kuyo (to mourn the unborn)." Though I am not religious, I had to do something to grieve. My partner hesitantly paid, questioning the price of a funeral for the unborn. "No," I replied, "It is a price for my grief that I cannot otherwise resolve." It was not the ritual that relieved me but the sight of all the little bodhisattva (Jizo) that stood behind the temple. Japanese patients didn't talk about it to each other, but now I knew that many also grieved just like me. There were toys and candies left next to the bodhisattva. I realized that I was blaming myself while the entire world told me to forget, overwrite and move on from my losses with another pregnancy. It was okay to remember them in this way. As my way of Mizuko-kuyo, I became a sponsor to Bangladesh children of all ages who had been born into poverty.

After my third loss months later, I became depressed. My thyroid was inflamed, giving me palpitations. It was as if my body was angry at itself for not being able to keep the baby in. Relief only came when I came across a collection of interviews of young children with prenatal memories. I was profoundly comforted by their statements, "babies (fetuses) choose their mothers, knowing their fate in



this world when they come into being.” I realized that I didn’t have to move on. These potential lives chose me. This time, I decided for the miscarriage to take its natural course instead of actively having surgery. It took a couple of weeks but I felt as though I fulfilled my responsibility as a mother.

Even after thorough blood tests, the cause of my recurrent miscarriages remains unclear. One hospital told me it may be immunological—natural killer cell activity increasing with the stress of being pregnant. After starting a regimen of mild immunosuppressants during my fourth pregnancy, my first son was born. I never had any subsequent treatments, and, two pregnancies later, I now have three children. My husband maintained indifference to all my pregnancies after my first loss. He pretended as if nothing was happening to me and kept our daily routines, like offering me wine or coffee whenever he was having one. He only became excited after he heard our children’s first cry. He did not want to be hurt again and he needed his distance from the pregnancies.

We are still grieving for those lost babies and that’s okay. We tell our children on their birthdays, “If it weren’t for them, you may not have existed.” I tell my patients my story so they may remember them too.



## Baby Judah and the Lessons We Take with Us

Daniel J. Hurst & Rachel N. Hurst

It was closing in on midnight. Patches of snow on the ground because, in Pittsburgh, they don’t completely melt until the spring. We wished we could be in bed. We wished we could be just about anywhere else—any other situation—than the emergency department exam room, with its fluorescent beams and sterility and solitude and silence.

The pain had begun earlier in the day. At first so subtle it almost felt imaginary, then gradually

building to a crescendo impossible to ignore. We knew something was off.

At the time, I (Daniel) was a second-year doctoral student in bioethics preparing to finish coursework, begin comprehensive exams, and hopefully be on the job market. We had hopes of enlarging our family. When we first learned that Rachel was pregnant, the emotions that followed were almost indescribable. Elation doesn’t seem like a strong enough word. We wondered at the thoughts of being parents, welcoming a new little life into our family, and all the joys that would accompany it. We told close family and friends—FaceTimed with our parents—all of whom rejoiced with us at a new grandchild coming into the family. But on a cold winter night, in an emergency department exam room, joy was shattered.

“I’m having a hard time finding the baby’s heartbeat,” the ultrasound tech told us with a tone of compassion as she read not only the images on the screen but also the anguish on our faces.

This was followed by the matter-of-fact emergency doc: “We don’t see a heartbeat on the ultrasound,” she told us. “This doesn’t look like it may be a viable pregnancy.”

Uncertainty was what was conveyed in this message, though the tone did not leave much room for hope.

What had been a mountaintop of thrill, marveling at the little life growing inside, was dashed in an instant. The highest of highs turned on a dime into the lowest of lows we had experienced in our young marriage with the news that this life inside may not actually result in a child that we would be able to hold, embrace, and watch grow up. We were unprepared.

We left the emergency department in the pitch-black darkness and quiet of the night, still unsure of what awaited us when we got back home. The doctor did not prepare us. There was no talk of what to expect. What one might feel. What one might see.

And so it happened later the next day. Our child was expelled from Rachel’s body and flushed.

Reflecting some six years later, there are two central elements that we want to highlight about

our story that we believe will be helpful for readers: community and the notion of pain and suffering.

### Community

For us, having a community of supporters during the immediate aftershock of miscarriage was essential. We were lost in a sea of grief, and they were present. Separated hundreds of miles from our families, our support was mainly from our faith community—a church we had gotten involved with immediately after moving to the city. Our friends prayed with us, they cried with us, they were present as a visible reminder that we were not alone in this grief, and they were willing, as much as possible, to walk this road with us. Knowing that we weren't alone didn't make the grief any less real, but it assured us that we were supported and that this baby would be missed dearly.

Miscarriage also prepared us. In the introductory phrases to his second letter to the church in Corinth, the Apostle Paul writes that God is the God of all comfort, and he “comforts us all in our afflictions, so that we may be able to comfort those who are in any affliction, with the comfort with which we ourselves are comforted by God” (2 Cor 1:4). What Paul is saying here is that our afflictions are, in part, meant to be able to comfort others when they go through similar events. Within six months of our miscarriage, both the friends that had introduced us to one another, as well as Rachel's sister, walked the same road of miscarriage. Because of everything we had been through, we were able to, we hope, provide them with words of comfort.

### Pain and Suffering

I (Daniel) am now a professor of bioethics and medical humanities in a medical school. In the required course on medical humanities that I teach, I typically assign Eric Cassel's classic 1982 article from *NEJM*, entitled “The Nature of Suffering and the Goals of Medicine.” Cassel's thesis is that pain and suffering are not synonymous. Suffering certainly may include physical pain, but also points to social and psychological realities that are more complex.

Cassel goes so far to say that a goal of medicine must be relief of suffering (not just pain) and that failure to understand suffering can become the source of additional suffering for the patient. There are lessons here in our experience. The ultrasound technician in the emergency department who told us she could not find a fetal heartbeat expressed compassion toward us, seeing not only the physical pain on my wife's face, but the pain welling up in our hearts, too. For the physician we saw afterward, a lack of fetal heartbeat was a clinical finding that simply needed to be stated, leaving an ocean of other elements unaddressed. Nothing about what to expect. Nothing about what to do. Nothing about what to feel. Nothing about what we might see as the body expelled our child. Looking back at this experience, now over 6 years ago, I'm still not quite sure what I would want from that physician, but a simple “I'm sorry for what you're experiencing” would have been a good start.

I (Daniel) have often described miscarriage as missing someone you never had the opportunity to meet. Grief isn't linear. We may go weeks without thinking about it but then something will remind us and the acute feeling of missing returns. We wanted to memorialize our lost child somehow. Naming him seemed appropriate. So, Judah, your mommy and daddy, and your two brothers, look forward to the day, in hope, of being reunited.



### The Thin Clear Drape

Elise C. Tarbi

“**B**aby's First Year,” the calendar proclaims, adorned with illustrations of giraffes and elephants in light pastels. On May 26<sup>th</sup>, next to a “One Month Old” sticker, a note reads, “Amanda died—SIDS.” On May 27<sup>th</sup>, another note, “Elise Smiles at Mom.” The notes are written in the same handwriting, my mother's. They use the same-colored pen. Side-by-side, unimaginable loss

and then (extra)ordinary joy, each day endlessly significant. This is how I entered the world, as part of a pair, and suddenly, without warning, alone; loss has been with me since the beginning.

When I first became pregnant, the revelry surrounding the phase felt foreign, alienating. I didn't want to read "What to Expect When You're Expecting." I wanted to read "What to Expect When You're Creating Inevitable Death and Entering a New Kind of Living." I Googled "miscarriage statistics by week" at night and bought furniture for the nursery during the day. I felt isolated in this messy in-between, a joyful uncertainty living in my body and seeping into my world. I contemplated how and when to share the news. Should I wait until the steadier footing of the second trimester? So that if the pregnancy ends, we can all go on pretending life is normal? So that I can shield others from the grief and pain we all wish to avoid? When I finally gave birth to my son, I stayed awake all night in the hospital, counting his breathing, watching to make sure death didn't come.

Later, after we had been trying to get pregnant for six months with a second child, I studied the faint pink line growing darker each day, and after the bleeding lasted for five days, I felt my heart break open anew. When I told people about our "early pregnancy loss" or "chemical pregnancy," or whatever is the chosen sanitized language for a dream deferred, the responses lacked the necessary compassion for the arduous process of opening ourselves up, again and again, to hope. A nurse at the midwife's office offered, "in the past, we wouldn't have even known you were pregnant!"—as if the pain could be erased by imagining an alternate reality where the pain didn't yet exist. I felt hurried back to normal as I added February 27<sup>th</sup> to the handful of dates in my internal grief alarm clock,<sup>1</sup> when my body reminds me of the trauma that lives there. And still, I held on to the dream of *becoming*, knowing

deep in my cells how temporary, how fleeting, the human form can be.

As a palliative care nurse practitioner, I've sat with many individuals with serious illness as they neared the end of their lives and reflected on their life's meaning. Both life-threatening and life-affirming, the prospect of death in serious illness has this way of refocusing. What's less talked about is the way that trying to conceive, pregnancy, and birth can provoke an adjacent phenomenon. Both life-giving and earth-shattering, death entered my thoughts each time I started trying to create a new life.

When I did become pregnant again, I let myself fully love this tenuous, little possibility, knowing too well that when we open ourselves up to love, we also open ourselves to loss. I tried to create space for this dialectic in my personal life and in the midwife's office. I started my first meeting with the midwife by telling them, "I am preparing for the worst." These dark truths often lurk unspoken with our health care providers as we talk about treating nausea (try B6!) and future genetic testing (check with your insurance!). The boundary between *existing* and *not* is as thin as the clear drape that hung between my second son and me as he was lifted out of my abdomen. He exists, and so do I. How wonderful, how terrifying.

What I have come to realize is that our stories about pregnancy or infant loss don't start or end with the loss. From the moment I began trying to conceive, in untold ways, on any given day, death made itself known. The monthly reminder of cell death during menstruation. The silence during the first scan when everyone collectively held their breath, waiting for the faintest heartbeat. The unbearable stillness after the first flutter of someone else inside my body. The absence of my child in my arms after birth when he was taken to the neonatal intensive care unit. Even the most "ordinary" pregnancy is steeped in fear of loss that is often ignored. These small encounters with the fragility of life, impermanence, and mortality, pass us by, unacknowledged. But we can make another choice because our grief eats away at us when it isn't shared.

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<sup>1</sup>I was first introduced to this term I didn't know I needed on Twitter by reporter Tina Vasquez: <https://twitter.com/TheTinaVasquez/status/1388941618632400896?s=20&t=5Gs9NaXuQxIr38CwFevyIw>

Pregnancy and parenthood are so often met with phrases that feel hollow and one-dimensional, “Congratulations! Enjoy every minute!” I want a richer, deeper vocabulary for the way we greet one of life’s great transformations. What I wanted to hear instead when I first became pregnant was, “How do you feel now that your body is molding another? Now that your heart is breaking into two?” and “Do you want to talk about what scares you now?” When I experienced an early pregnancy loss, most of all, I wanted people to sit with me, in silence. And then I wanted them to ask about my dreams. “Who did you imagine this person might become? Who did you hope you might become too?” When I became pregnant again after loss, I wanted people to say, “How brave of you to try again,” and, “do you want me to hold some of your worries for you?” The intimacy with life and death, the joy and the grief, it’s all a part of our unpredictable, uncontrollable parenthood story. I wanted people to say, we accept your invitation to join you in the expansive “and”—of holding life *and* death, the joy *and* the grief—and we can weave this story with you.



### Clinicians’ Unintentional Lack of Support through Pregnancy Loss

Katarina Lepinski

**H**aving lost all four of my pregnancies, I have a lot to say about the support, or often lack thereof, I’ve received from my care providers and various clinicians. Ranging from lack of empathy and sympathy to downright insensitive phrasing and judgement, I can’t help but feel like a burden to the nursing staff and doctors that I’ve interacted with.

The responses I received were often negative and cold; I received very little compassion from most of the clinicians I interacted with. Of the four times that I’ve met with an OBGYN following a miscarriage,

only two were addressed with an “I’m sorry for your loss” from the nursing staff and doctor.

When I called my OBGYN’s office to discuss minor spotting during my first pregnancy, I was met with an extremely cold and rude attitude. I had called the after-hours emergency line, as I had noticed the spotting early in the morning and before the regular nurse line was available. The woman I spoke to made me feel like a total inconvenience—she told me to call my OBGYN’s office after 8 am. She didn’t even address the reason for my call. I felt ignored and helpless. Just because there wasn’t anything she could do, a little compassion would have gone a long way. As I hung up, I remember asking myself, “What’s the point of an after-hours emergency line if they can’t do anything to help? She could have at least attempted to comfort me.”

Later that morning, just after 8 am, I called my OBGYN’s office. I was again met with the feeling that I was an inconvenience. This nurse told me that I shouldn’t worry myself over “nothing.” I understand that a lot of women (and men) carry anxiety through their pregnancies and she was correct in that I shouldn’t worry about “nothing,” but I know my body and I knew that something was wrong. Her tone stung—it wasn’t a “it will be okay” sort of “don’t worry,” it was the “get over it” sort. Her not taking me seriously broke my heart; I felt stupid for asking for help. She explained to me that I had just taken a blood test a few days prior and that the numbers were good. First, I knew that I was about five weeks along as of the day of that blood test; when they called me with the results, they said that the numbers looked good for being four weeks along. I remember how wrong their statement felt, but I didn’t correct them. I assumed they knew something that I didn’t. I now understand that some women ovulate later in their cycles, which could mean that they’re not as far along as they think they are, using the first day of their last period to calculate it. Did they attempt to explain that to me? No, of course not. I know that I didn’t ask for clarification, but you would think that they’d want to *educate* me, especially with it being my very first pregnancy. They could have taken a literal minute to tell me that, based on the first day

of my last period, I could be five weeks along, but not having known when I ovulated, I could be just four weeks along. I sometimes think that I expect too much from my care providers, but at the same time, shouldn't I be able to trust them to give me the whole story?

I had to beg the nurse to let me come in for a second blood test but was told that it wasn't necessary (since my numbers were "good" a few days prior). After begging, she told me that if it would make me feel better, they would let me come in. Why did it feel like I was asking too much? What did it matter to her if I had to pay for a second blood test; why didn't she take me seriously? It's common knowledge that the HCG numbers double every few days in a healthy pregnancy. Why was it too much to ask to test the numbers again a few days later? Enough time had passed that there would have been a change in the numbers, one way or another. Why didn't she want to calm my nerves, if she was so sure that everything was okay?

That second blood test revealed a miscarriage. When the same nurse called me with the results she didn't hide her surprise; she was so sure that I was overreacting that she actually said "... *Oh...*" before revealing the negative results to me.

\* \* \*

Many medical terms are antiquated and hurtful, such as "habitual aborter" and "chemical pregnancy." While I understand that these terms make sense on a medical level, it hurts to have the professionals I'm supposed to trust with my care use such terms. At one point, to summarize my history of miscarriage, a nurse spoke out loud as she wrote "two previous pregnancies, no living children." Is there not a softer way to address my medical history?

I've met with two different OBGYNs. The first one I met with was experienced and had a wealth of knowledge, but I didn't feel that he was the best fit for my situation. He was very clinical, and I needed more emotional support than he provided. This isn't to say that he isn't a great doctor, he just wasn't meeting my needs. That all being said, when entering my appointment summaries into my patient portal, he always used the diagnosis of

"pregnancy loss" or "recurrent pregnancy loss." I didn't think anything of these diagnoses until I met with the second OB.

The second OBGYN was more friendly and caring than my first. She ended our first appointment with "I'm a hugger" and gave me a warm hug. However, when I reviewed my patient portal following my first appointment with her, I saw that she used the term "habitual aborter" to diagnose my condition. This was the first time I had been called a "habitual aborter," and it stung. It still stings. She could have used the same terminology that the first OBGYN had used, I know those terms were available options, yet she chose one of the most hurtful terms I've ever seen. Even those that haven't experienced a miscarriage (let alone recurrent miscarriages) cringe at the term.

\* \* \*

I meet with my primary care physician once a year, generally sometime in January. I had seen her just before our first miscarriage, so by the time I met with her the next year, I had experienced two of my four miscarriages. At that appointment, without prompting, she told me that she was sorry to hear of my losses. She asked if we had a plan in place, in regards to testing for answers. At that point in time, we weren't pursuing any testing, as it's not recommended to test for issues until after a third miscarriage. I understand that two consecutive miscarriages can be "just one of those things" but being told that we had to go through the emotional trauma of a third loss before being encouraged to find answers was isolating. There's a fine line between what's medically necessary and what's emotionally necessary; medically, after two miscarriages, there isn't *really* an issue, but emotionally it was all a very big issue. Feeling that I wouldn't be taken seriously until a third loss was so frustrating, but it was what it was.

When I met with my primary care physician the following year, she was surprised to hear that I had experienced another two miscarriages. This was surprising—why did she review my medical history last year but not this year? Why were two losses worth acknowledging, but not four? It sometimes feels as if health care providers equate



“uncommon” with “impossible.” Was she so sure that I would only have two miscarriages that she didn’t bother to review my information prior to that second appointment?

\* \* \*

Not only does it feel as if my care providers often lack compassion and empathy, it also feels like they lack a sense of simple thoughtfulness. When I first call my OBGYN’s office to report a positive pregnancy test, three appointments get scheduled—1.) the first blood test to confirm the pregnancy, 2.) an educational phone call with a nurse, and 3.) the first appointment with the OBGYN in which you hear the baby’s heartbeat.

When I then call to report the start of a miscarriage, I’m asked if I’d like to have a follow-up appointment with the OBGYN to discuss our loss and potential next steps. The first two follow-up appointments were general and clinical. The third and fourth were geared more toward the next steps and recommended testing.

The appointment that is initially scheduled for the purpose of hearing the baby’s heartbeat becomes that follow-up appointment to discuss the loss and potential next steps. I understand that this is for convenience, and I haven’t objected to keeping the appointment, but why isn’t it common practice to cancel that appointment and schedule the follow-up for another day? Keeping the appointment on the same day is devastating. I get to sit in a waiting room full of happy couples and expecting mothers, alone and grieving.

My third follow-up appointment was a chaotic mess. A few days prior to the appointment, I had confirmed that I would be there via text with the clinic. The morning of the appointment, I logged in to my patient portal to confirm the time and location; as of that morning, the appointment was still reflected in my portal.

When I arrived at the appointment, the check-in desk told me that I didn’t have an appointment on the calendar—they could see that it had been canceled, but not when it had been canceled. I told them that I had confirmed the appointment and had just seen it online a few hours prior. They told me to head down the hall to my OB’s check-in desk

and discuss the cancellation with them. When I spoke to the receptionist at that desk, they asked me who I had talked to that morning to cancel the appointment. I explained in frustration that I didn’t talk to anyone, no one called me, and in fact, I had confirmed the appointment via text.

As the appointment had *just* been canceled, the OBGYN was still available to see me, so not all was lost. He apologized for the mistake and explained that someone had neglected to change the coding of the appointment; someone saw that the appointment was coded as a first appointment to hear the heartbeat but that I had a note on my file that I had miscarried. Could they not see that I had confirmed the appointment? Why didn’t they just call me to ask me if I had planned to come in that day?

Why do so many people make assumptions about miscarriages? Why is it so common, yet so misunderstood?

I know that doctors and their staff often do the best they can with the time and resources they’re provided. That being said, a little compassion would go a long way. It’s not that I’m expecting OBGYNs to be therapists for their patients, but shouldn’t it be part of all physicians’ training to be compassionate? I also understand that mistakes happen, but communication is key. The words that my doctors use matter. Phrasing matters. Compassion matters.



## Sacrifices

Efrat Lelkes

I’ve always been goal-oriented. Since I was a teenager, I’ve known what my life would look like five, ten years ahead of time. I went straight through—straight to college from high school, to medical school, through residency, fellowship, and to a junior faculty position in academia. I never stopped to ask if this was the right path for me, nor did I ask what I was missing throughout this path.

For me, the honor of being in academia meant that I kept going without questioning. I theoretically knew that sacrifices were intrinsic to becoming a physician, especially a physician-scientist. But to be an academician, I believed, was what I was supposed to be, and thus I knew that I would sacrifice sleep, money, and a “normal life” for a long time.

I just didn’t realize that I would sacrifice myself.

In my mid-thirties, I began to recognize that the life I had forged as a physician-scientist was destroying me. I hated being in the lab. I missed my patients. I spent my time away from work living a very unhealthy life. And so, abruptly, I left the lab and my career as a scientist, and I transitioned to being a full-time pediatric critical care physician. I did so with the belief that I was a failure. I did so without considering the need to care for myself and to truly ask what I needed. I just believed I needed to serve others. The pressure I put on myself was immense. I started to mistrust myself as a clinician. I started to make mistakes. I deeply despised myself. And then I broke. With severe depression and anxiety, post-traumatic stress disorder, and a need to run away, I left home for a year under the guise of further training in palliative medicine. It was the year that saved my life, and it was the year that I began to appreciate how much I had given up for this career. It was when I learned that academia was not life, and it was then that I learned what I truly wanted.

I wanted a family. I had wasted so much time pretending that I didn’t. No glory had been afforded—especially for young women in this world—to needing a companion. I was supposedly superhuman; I didn’t need anyone else—whenever anyone asked what was wrong, I would defiantly aver that I was *fine*—and to suggest otherwise meant that I was a burden and useless. But, by my late thirties, after my year away, after starting to heal, I was learning otherwise. I wanted to belong and to connect. I wanted a partner. Just as much, I wanted to become a mom. So I entered the world of fertility, deciding to become a single mom by choice. My reproductive endocrinologist was remarkable, my friends and my family were supportive, and I felt courageous, proud, and ready.

And, just as I started this process alone, I fell in love for the first time. I met a man the same month I started to try to get pregnant through Intrauterine Insemination (IUI). The first cycle did not work. I was sad, and he supported me. The second cycle did not work, and I was relieved. He was as well. We were becoming part of each other’s lives, and we were excited about the future. I chose to put motherhood aside to focus on us, in theory. But, in truth, it was hard not to think about it daily. I knew that I was getting to the end of my reproductive years. Though I wanted a fairy tale, and I wanted us to be together, the aching to be a mom would not subside. I tried to quash it, but it would bubble up, and it would explode. I should have listened to him when he told me he was not ready. We perhaps should have made different decisions about our relationship. But we were deeply in love, we believed in us, so we forged ahead.

After an eternity of pressure by me—and pressure fueled by the pandemic—he succumbed. He told me he was ready to start trying. We did, and, immediately, we got pregnant. And, immediately, he realized that he had made a mistake. The pregnancy was thus tainted from the beginning. I was furious at him for not being ready. He was furious at me for pushing him. I was also exuberant; it was magical to feel my body change, it was remarkable to dream about being a mom. I called my closest friends. We all cried together—bittersweet tears for me, tears of joy for my loved ones. But I could not talk about it with him. He was seething.

Together, at eight weeks, we went to our first ultrasound. In the waiting room of radiology in my hospital, I was joyous and he was distant. We were brought to the back and the ultrasonographer began her study. She and I chatted at first. I was thrilled to see the little embryo within the sac in the uterus. Soon, the tech became silent. I asked a question about the heartbeat—when would I see one, since I couldn’t? She gave an absurd answer about the doppler being too strong, but I was in denial, so I did not question her. She left the room, and I kept up a cheery disposition. After a seemingly long time, the attending radiologist entered the room. And, then, I knew. She showed me the images, explained that

the embryo was measuring a bit small, which wasn't too concerning, but what was concerning—and I completed her sentence—no heartbeat.

My eyes welled. He collapsed, put his head on my chest and cried. I focused on the radiologist. Her bedside manner was perfect—in palliative care, I train others to be as skilled. It was surreal to note her kindness, her compassion, her presence as she told me that I had miscarried, but I needed to focus on something other than the sadness.

She left the room. I crumpled in tears. He held me. The tension between us—an unspoken distance—dissipated. I was terrified to walk through the hallway, afraid to run into friends, so we snuck out the back. We went home. I felt helpless. He sat by my side, on our beautiful deck with the picturesque view, and I called all my loved ones. One by one. To tell them I had been pregnant. I no longer was. I felt so empty and yet so aware of the dead thing inside of me. I needed it out immediately. I scheduled a D&C for that week. And I was destroyed.

And, for a long time, I still was. Our relationship ended. He moved out, and I still miss him every day. I am alone—without a partner, without a child. I am now on the excruciating IVF journey. The rollercoaster of injections, of excitement, of disappointment, of the financial implications, is simply brutal. I think constantly of my pregnancy, however short it was. It pained me for months when friends would tell me that they were pregnant. I enclosed myself with friends also on the IVF journey, and I relished my time with women who understood miscarriage, who understood the need to be a mom, and the cruelty of not being one. I tried not to cry at work, surrounded by children. I failed, often. When my due date passed, I felt numb. Each month that went by, I thought of holding that baby. Of who that baby would have been. I felt more alone than I ever have.

And I was furious. I still am. I am angry at this system, a system that thrives when we sacrifice everything. For this profession, I forewent the normal developmental stages of being a young adult, of early romances, and of learning how to care for myself. I gave my reproductive years to this career and to my institution, an institution that, despite

happily taking those years from me, refuses now to assist me. I am made to feel like it is my fault that I am struggling to become a mother, that I should have tried earlier, perhaps, that—perhaps—there is something wrong with me. But I could not have tried earlier, and there is nothing wrong with me. This system broke me. And I am now healing myself. I know now that it was not my fault that I am not yet a mother. I know that I am not alone on this path. I know that I will be a mother, one way or another.

And I am no longer willing to sacrifice a thing.

## Commentary

# Ethical Response to Perinatal Loss— Communication Is Nearly Everything

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**Conflicts of Interest.** The author reports no conflicts of interest

**Keywords.** Pregnancy Loss, Miscarriage, Narrative Ethics, Perinatal Bereavement

**Abstract.** There are more than 800,000 pregnancy losses in the US each year but the numbers do not explain the lived experience of loss. Twelve authors shared deep and descriptive accounts of their losses and as a commentator, I elevated specific themes from their writing to apply an ethical lens. Depth of grief, poor communication from care providers or others, testing and the disposition of fetal remains, fear, sense of failure, and an important missing component—miscarriage or fetal death in the context of a pregnancy that was unwanted—are considered.

This collection of narratives is an ideal starting point for considering how an ethics lens might assist in understanding parents' experiences with perinatal death. In their narratives, the authors offer vivid descriptions of learning about, coping with, and later integrating perinatal loss into the story of their lives. I have faith in this process and hope that through my experience working as a perinatal bereavement coordinator and ethics consultant, I can reflect on these narratives and offer steps to optimize ethical care and minimize the harm inflicted when perinatal loss occurs.

Beauchamp & Childress' ethical principles of beneficence, nonmaleficence, autonomy, and justice are applied to these narratives in an uncomplicated manner (2013). Beneficence requires us to do good when preparing and caring for perinatal death. An example would be thorough education that

prepares staff for working with individuals who experience perinatal death before any cases arrive. Nonmaleficence requires that we do not harm people in the course of caring for them. In perinatal death, nonmaleficence most often presents itself in well-considered, expert communication skills, so that inappropriate or dismissive comments do not retraumatize people who are already hurting. Justice is served when efforts to advance equity influence hospitals to provide pathways for patients and families to obtain needed genetic testing, secure affordable disposition (e.g., burial or cremation) of the fetal remains, or receive care that respects their culture, religion, and individual communication needs. Autonomy can be optimized when calm, thorough, and well-timed explanations are given so that women and families can decide what bereavement interventions to accept, which will allow

them to cope momentarily and lend credence to an eventual feeling that they parented well in the midst of their crisis.

### **Depth of Grief**

Our culture seems to discount early perinatal loss for some reasons and later loss for other reasons. But all loss causes pain. Early pregnancy loss happens frequently; thus, some think it should be expected and not seen as difficult. Conversely, our flawed cultural narrative is that late pregnancy and neonatal death rarely happen, which often leaves families unprepared and feeling personally responsible when it does. But largely, the authors of these narratives did not expect their pregnancy losses and were often shocked by the news or discovery. When speaking of her early loss, author L. Emily Cotter shares, “The grief felt immense . . . my heart shocked and devastated, my mind wearied and numb.” Christina Mulé echoes this feeling. “I tried not to cry, or maybe I was too shocked to respond.” Aside from her initial shock, Mulé shared she was confused and scared. Despite being a traumatic experience for Mulé and her husband, she says the doctor scheduled to do her surgery seemed to act like this was “just another miscarriage.” Even while pregnant with a subsequent and healthy pregnancy, the thought of her losses left Mulé crying “hysterically.” She ends her narrative by saying, “[W]ith time and the impending delivery of our baby, we are hopeful that our hearts will mend.”

Author Angela Dahm described an earlier loss before her stillbirth as “. . . excruciating and traumatic. I grieved this loss deeply.” Often, women I care for describe the time lived between an early loss and the looming due date, similar to Giulia Faison, who shared that “every moment in time was tied to the life that had been lost.” The many discounting comments our contributors mention receiving, such as “only” a certain number of weeks, or “not a baby yet,” or the endless “at least . . .” comments, are common. These comments are nearly universal to any woman who has ever had an early loss. Yet, they happen in the same culture where Jill Wieber Lens observed, “Great lengths are taken to prevent the abortion of a 6-week embryo, but very little (if

anything) is being done to prevent . . . stillbirth at 37 weeks.”

When I teach healthcare workers about perinatal loss care, I often get questions from those who do not yet understand why some experience early loss as painful. One method I use to explain this is to write the number 60,000 on the whiteboard. I tell them that during pregnancy, the idea of being pregnant went through my head—for at least a split second—every waking minute (and some sleeping ones) of every day. By the time I lost one of my pregnancies at nine weeks, I had thought of a wee person (who I had expected to forever be in my life) at least 60,000 times. My inner working thoughts were similar to Jessica Bratt Carle’s: “During that time, the daunting reality that my body was playing host to another person’s life was never far from my mind.”

### **Poor Communication from Care Providers and Others**

The principle of nonmaleficence guides caregivers to give bad news in the least harmful way possible. Yet, Lens gives us a vivid description of her screaming in despair after figuring out that the earlier bedside assessments meant that her son Caleb had died. The fact that she was the one to reach out to her doctor to let him know the situation and that she had to wait hours for confirmation all made her learning of her son’s death worse than it had to be. I teach caregivers that no one should ever have to connect-the-dots that their baby is dead. The perinatal period is the time of childhood with the highest morbidity and mortality rates; thus, those who practice this care need to give bad news frequently enough that proficiency is imperative (Leuthner et al., 2020).

Rose Bendas received the news of the likely death of her baby more directly but perhaps painfully so. The fact that her care 32 years ago left no option for a confirmation ultrasound study to confirm the death until the next day is likely shocking to younger women accustomed to the frequency with which ultrasound exams are currently done. I thought that part of her story couldn’t get worse until she said there was an hour and a half wait for the physician to tell them the baby had died.



“It just looks like schmutz” was a sadly insensitive and unprofessional way for the resident to communicate to Faison that her embryo had no hoped-for form and had likely died. An absence of immediate reaction from our contributor to her caregiver may have left the caregiver with the false impression that her comment was not inappropriate. Perceiving tragic news often causes a trauma response and “survival mode,” so Faison’s lack of a justified reaction in expressing her angst over the resident’s words is not a surprise (Davis, 2016, p. 49).

Jessica Bratt Carle went to an appointment after days of bleeding, hoping to find calm compassion but her doctor was “chipper,” and spoke of the frequency of miscarriage seemingly before Carle and her husband had fully been told that the outcome of her pregnancy held no hope. The response they received was inappropriate, considering their level of grief and the depth of their sense of loss.

Monica Snyder received news that one of her twins had died from the ultrasound technician, who seemed to think that mentioning the loss was reasonable as she did not expect the patient to “really freak out.” Cotter also gives examples of staff guessing what her reactions would be, which were often inaccurate. Faison describes clearly why poor communication hurts after perinatal loss “The value judgment others place on a woman’s loss is not just irrelevant; it is painful, harmful, and helps to irrevocably disjoin the person from her surroundings. No bridge exists to connect the two if the gulf of trauma is not supported.”

Carle provided examples of good communication and truly beneficent care in both the care she got at the time of her stillbirth and the care she was able to give when it was her turn to serve. Dahm was also the recipient of compassion, accompanied by the right words to help her in her worst moment. Their stories exemplify what can happen when caregivers are prepared and willing to listen and respond compassionately and appropriately.

### Testing and Disposition Options for Early Loss

Snyder does a thorough job of describing the sadly-typical confusion and complexity that a woman is

likely to confront if she has specific requests for the remains of an early pregnancy loss after a dilation and curettage (D&C) procedure. Healthcare has mostly failed the childbearing community regarding this (Ruiz, 2012). Snyder described well the labyrinth of logistics, rules, limitations, and errors common when women seek to satisfy specific goals in early loss, such as genetic testing or specified disposition of the remains of the pregnancy. Staff being uninformed and having no accessible go-to person is common but could be improved.

Historically, hospital and local regulatory systems were set up to remove parents from decisions about fetal remains disposition. In the 19<sup>th</sup> century, parents were pressured to donate their deceased fetuses to their doctors, who used them as specimens of scientific study (Withycombe, 2019). This is how fetal remains initially became identified as “medical waste” (Morgan, 2002). More recently, pressure from parents and perinatal loss professionals has influenced state laws and hospital policies to return decisions to mothers or parents (Levang et al., 2018). It is clearly an advance of autonomy to respectfully allow women and families to make disposition decisions for themselves but these conversations need to be sensitive and respectful about the state the patient and family are in.

Snyders experience is common. Her suggestions are good and can be defended in the ethics literature that parents’ autonomy ought to extend to this area (Engelhardt, 1996, p. 256). Hospitals need a core of staff with working knowledge of laws and policies applicable to the disposition of fetal remains. Administrators should be willing to update existing policies when they limit the freedoms that state law intends families to have in choosing disposition options after perinatal loss.

### Fear

Seven of the 12 contributors mentioned fear surrounding their pregnancy losses, yet none mentioned that their caregivers asked them about it or discussed with them that fear is a common feeling. Bendas’ husband asked her if she was scared. This is an amazingly supportive question from a partner.

When I meet up with a woman before delivery or at admission to Labor and Delivery for an induction, I bring up fear. In caring for many women having an induction after a loss, I have come to see that sometimes sadness and fear mix together. I recognize that sadness is an unavoidable part of the experience and think it would be disrespectful for me to try to make someone not feel sad. Fear, under these circumstances, is often a fear of the unknown, and some unknowns actually do have answers. I ask my patients to try to recognize fear and share it with me. I tell them I will help them learn how to deal with it in the best way for them.

Like a few of our contributors, parents tell me they are afraid of what the baby will look like and if they should hold the baby. I let them know that they don't have to decide about holding the baby yet. When the baby is born, we can give them a truthful but gentle description of what the baby looks like. The decision can be made then. Regarding other fears, patients have told me that they are afraid that we will throw the baby in the trash and a clear explanation of our normal processes soothes that fear. I have had patients, particularly from underserved groups, express fear that the staff will blame them for a death and be mean, which will not happen when staff receive training and education on how to appropriately respond. We discuss how to explain the death to their other children, why avoiding baby showers may be best for the immediate future, and how to respond to people they run into at the store. I have never had a person tell me they don't want to talk about fear. By dispelling fear, I help women and their partners learn what data points they need to make the best decisions for them and maximize their autonomy in the active process of dealing with death.

### **Sense of Failure**

Our cultural narrative is that those who do the right things get the right results; thus, parents often infer that their baby's death is their fault. Our authors shared these sentiments. "I concluded it was my fault" (Mulé). "My body was the scene of his death" (Lens). And "I lost my faith and hated God

for not finding me worthy enough to be a mother" (Sirena Washington). I have heard self-recrimination described in countless ways. We tell parents the death was not their fault but that rarely sticks. Research shows that "esteem building is a potential insulating variable" from distress in infant death (Hill et al., 2017). Esteem can be built in simple ways like Bendas' example of finding peace in her decisions or more elaborately like Dahm who arranged a sibling visit and photo shoot with her baby. I transparently share my goals with and for the women and families I care for: "my goal for you is that, if we were to speak two years from now, I hope that you can say to me 'when I look back on the experience of the loss, I now know that I did a good job, I am proud of myself and I am happy with the decisions that I made in the moment.' How can we as a team care for you so that you can say that?" Nothing can fix death and grief, helping individuals who experience pregnancy loss see themselves as good parents to the baby in the moment can facilitate positive long term psychological healing, which is surely a good thing.

### **What Was Left out of These Narratives: The Missing Component**

All of the stories in this collection detailed experiences of loss with wanted babies, where mothers planned to maintain the pregnancies if possible. Helpful tools for communicating respectfully with parents experiencing loss in this context have been reviewed here. However, those who care for patients experiencing pregnancy loss in general hospital settings such as in Emergency Departments are likely to interact with women either having complications from medically induced abortion procedures or spontaneous loss where abortions were planned. Like the contributors to this project, most women see the experience as a serious loss; however, approximately 25% will not see it as a loss, and some may be genuinely relieved (Catlin, 2018). Pregnancy loss patients must be approached in a way that respects that they are coming to the experience with a history and mindset all their own. It is just as inappropriate to assume that a patient having

a loss sees it as the death of a baby and is grieving as it is to believe they will or should move on swiftly without fear or mourning (Littlefield, 2017).

When responding to a case where it is unknown what emotional state the patient is in, one option is to reference “the pregnancy” to the patient and await a response; the patient may refer to the “baby” or to “it,” which will provide some context to the patient’s feelings (Limbo, 2017, p. 8). It is also reasonable to be transparent and communicate that parents having early loss experience a wide range of circumstances and reactions. If the parent chooses to share with you what this pregnancy means (or does not mean) to them, you will be better prepared to meet their specific needs.

## Conclusion

So much of the failure or success in caring for the women and families in the stories shared by our contributors hinged on good communication. I propose that these are learnable skills and those we care for desperately need us to be the ones to build a bridge of communication with them when they are in crisis. Some authors eventually found healing after making space for their grief and experiencing connectedness with other parents who had suffered a loss. For communicating at the time of loss, Cotter gave us specific examples of communication failures; however, she also offers a solution: “Greet each encounter with curiosity and generous listening.” People can sense your willingness to hear them. Sit down, do not be frightened away by their tears, be patient, and listen. You may be the person they are thankful to have had present for them for the rest of their lives.

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## Commentary

# Held and Heartfelt: Compounded Grief in Healthcare Professionals' Experiences of Pregnancy Loss

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**Conflicts of Interest.** The author reports no conflicts of interest.

**Abstract.** The loss of a pregnancy can be an emotionally traumatic experience and the support or lack of support from professional care providers and systematic barriers within healthcare organizations impacts the grieving trajectory. Nearly half of the Narrative Inquiry in Bioethics story authors in this symposium indicated that they were healthcare professionals, which, to their surprise, did not buffer the shock and emotional trauma of the loss. For this subset of authors, reflections on the assets and perils of this juxtaposition in the caregiving dyad revealed unique professional and systematic practice gaps and presented opportunities for improvement. Themes of secrecy, shame, and guilt surrounding reproductive loss have been documented phenomena in research. Self-blame and complicated bereavement were also implicit topics in many of the stories where esoteric knowledge of healthcare structures and professional roles was present. Given the role that affiliation had in the healthcare professionals' stories, further research on the impact that occupation may have on prolonged or complicated grieving related to pregnancy loss should be considered. This analysis provides a unique opportunity to recommend improvements in the supportive care provided to those experiencing pregnancy loss and reproductive grief.

**Keywords.** Grief, Perinatal, Miscarriage, Disenfranchised, Physicians, Chaplains

## Introduction

**P**erinatal loss impacts many, with domestic estimates exceeding 2.4 million pregnancy losses each year, and yet there is a pervasive silence on the emotional impact that these losses induce (Ely & Driscoll, 2021). Healthcare professionals are often first responders to those losses, and research has suggested that many feel

under-equipped to engage in beneficent perinatal bereavement communication and care (Gandino et al., 2019; Haug et al., 2018). Because of the frequency of pregnancy loss, researcher Farren and her colleagues (2016) suggested that healthcare providers may become accustomed to them, especially when the loss occurs at an early gestation, which can lead to the omission of screening for psychological

sequelae at follow-up visits. Care providers specializing in maternal-child care primarily focus on fostering a wellness trajectory at the beginning of life. They may find the emotional trauma of pregnancy loss is paradoxically challenging, particularly if their training on end-of-life and perinatal bereavement care was minimal or absent. Grief and emotional reactions to reproductive loss have not been thoroughly researched. As a result, standards of care for reproductive grief remain deficient. Sharing her motives for telling her story Synder wrote, "I hope the medical community can learn from my experiences to better support other loss parents."

Nearly half of the stories' authors indicated that they were healthcare professionals. Their narratives resonated similar themes. Three authors were physicians or healthcare providers and two were hospital chaplains. These five stories provided intimate insights from parents who in the midst of an anguishing loss, assumed the role of patient and encountered their occupational peers as caregivers. In a juxtaposition, a few of these authors also examined their own previously held erroneous presuppositions about the patient's experience of reproductive loss. For instance, Faison, a perinatologist, compared her physician's response to her miscarriage with her own past spurious assumptions, admitting, "Certainly, looking back, in any other circumstance with me *not* being the patient, I would have thought those words were expressing empathy and hope."

### Trauma of Perinatal Loss

Research indicates that reproductive loss and its associated grief can be emotionally traumatic, prolonged, and contribute to maladaptive biopsychosocial outcomes (Berry, 2022; Grauerholz et al., 2021; Jaffe & Diamond, 2011). The extent of the impact is not necessarily linked to the gestational age of the fetus but to the attachment, hopes, and dreams the parents had for their child. Carle eloquently shared about the depth of the maternal bond in her experience, "I may have only been ten weeks along, but my mind and my heart had turned their attention to all that this new role and identity would ask of

me. When my uterus said 'never mind' to that first brief pregnancy, the possibility for that baby left my body, but the mother in me had already taken root."

The hurtful and irreverent responses from healthcare professionals that care for patients experiencing pregnancy loss can contribute to the anguish and trauma (Bellhouse et al., 2019; Lang, et al., 2011). A recent scoping review revealed that a significant number of parents who endured a perinatal loss at any gestational age met the criteria for post-traumatic stress disorder (as high as 60% in some studies). The review also found that the role of the attending healthcare professionals had a pivotal influence on the parents' reactions to the loss (Berry, 2022). In a national survey of those who had experienced miscarriage, "37% felt they had lost a child, 47% felt guilty, 41% felt alone, and 28% felt ashamed" (Bardos et al., 2015, p. 2). Feelings of guilt, shame, and self-blame are also pervasive with stillbirth (Duncan & Cacciatore, 2015). Along with the death of an expected child, perinatal loss has been shown to include an ontological death, which is a disruption of the parents' worldview of what they perceive as meaningful in life (Berry, et al., 2022).

### Disenfranchisement of Perinatal Grief

The grief experience related to pregnancy loss is often minimized or ignored by society and the healthcare professionals who provide care (Bellhouse et al., 2019; Lang, et al., 2011). Early pregnancy losses are more vulnerable to being disenfranchised, unacknowledged, or dismissed because of the ambiguous nature of the loss (Doka, 2016; Evans, 2021). Carle described how her grief experience after an early miscarriage was minimized compared to later pregnancy losses, stating, "There's a real disenfranchising of certain kinds of grief, where it's easier to recognize the magnitude of some losses and minimize others." Carle also observed that the reactions of professional caregivers to the loss do, in fact, impact the grief experience of their patients. She added, "The thing is, patients who are in unfamiliar territory are taking their cues from what's going on around them, trying to gauge a proportionate response." Disenfranchised grief



can precipitate longer grief trajectories and maladaptive sequelae (Grauerholz et al., 2021). Faison concluded how the disenfranchisement of one's grief adds to the trauma of early pregnancy loss, "The value judgment others place on a woman's loss is not just irrelevant: it is painful, harmful, and helps to irrevocably disjoin the person from her surroundings. No bridge exists to connect the two if the gulf of trauma is not supported."

### Knowledge vs. Experience

As a healthcare professional, there is a sense that knowledge about and encounters with illness, trauma, and loss would provide the necessary resilience and even infallibility when a loss is personally experienced. The healthcare provider authors expressed their dismay regarding the anguish and grief related to their own perinatal loss. When Carle encountered grief after her miscarriage, she surmised, "As a seasoned hospital chaplain in my late 30s, I was no stranger to medical settings and terminology, nor to death, grief, and the myriad ways people deal with unexpected sorrow. . . . My familiarity with the healthcare system didn't do me much good—no clinical observations or detached analysis were going to help me muddle through the emotional soup I was experiencing." A pervasive theme emerged about the sense of incredulity toward the suffering that accompanied the loss in most of the stories in this series, perhaps because of the overarching social narrative in health care that miscarriage is common and relatively simple to manage. The emotional aspects of miscarriage are not included in current miscarriage care guidelines for obstetricians (American College of Obstetricians and Gynecologists' Committee on Practice Bulletins—Gynecology, 2018). In a different approach, Ciaccio wrote about changing her career to become a hospital chaplain in order to make sense of her loss and foment her healing. She surmised, "I left my job at the state with its cushy benefits and security to pursue the call to care for others, and I wanted to be the one who sat with someone who lost a child too. My loss would mean something. It had to."

### Control vs. Vulnerability

Similarly, the theme of maintaining control for healthcare professionals who have mastery of knowledge and experience with healthcare delivery contrasted with the unanticipated experience of vulnerability and loss of control. Faison revealed her initial reactions as she disclosed, "I burst into tears. [My boss] told me to go home. Of course, as physicians, our training brands us with a work ethic that surmounts all else." There was interior tension with the lack of control and unpredictability of pregnancy loss and grief. Cotter said, "I tucked my grief away, only to have it surprise me in a poem referencing pregnancy loss or after receiving an off-handed comment about having another child."

### Depersonalization of the Unborn and Perinatal Loss

The healthcare professionals reflected upon the filial attachment they had with their unborn children, which was lost during their pregnancies. To the authors, the significance of their pregnancy expectations and grief intensity was independent of the gestation. There was frustration and sorrow about the trivialization of their experience and the loss of their desired children. For instance, Faison was stunned and crushed when her embryo was described as "schmutz" by the medical resident performing an early ultrasound. Carle elaborated about how the focus on the physical and technical aspects of the care plan denied the child she anticipated their dignity and ignored her anguish. She reported, "There were some statements about how common miscarriage is, how seldom people find out a cause, and some guidelines for what to expect as my body expelled the pregnancy . . . My world had stopped, but [my doctor] had to move on to the next billable encounter . . . The implicit message I got from my OB was, *this is not really a big deal*. Like, note to self: it is not okay to come undone right now." Mulé underscored how reproductive loss and grief are disenfranchised when she concluded, "To [my doctor] this was just another miscarriage and just another procedure, but for me, this was my baby

and all of our hopes and dreams.” Having given birth to one child, Faison later suffered numerous pregnancy losses. She elucidated upon the experience of grieving a miscarriage that was minimized not only by her providers but also by family and friends with whom she shared her loss. Faison said she received “a slew of entirely unhelpful and insensitive comments” and provided examples: “At least you have a child” or “At least you know you *can* carry to term.” In reflecting on these hurtful comments, Faison explained, “A loss is a loss. It merits mourning and grieving. To me, life has intrinsic worth. These comments seem to imply that worthiness is quantitative; the more children you have, the less important they become.” She went on to describe the depersonalization that occurred and how she only found solace in connecting with other women who allowed her the space to grieve.

### Caregiving Dyad Juxtaposition

Many of the discourses by healthcare professionals described how occupational affiliation shaped their introspection and outlook on the pregnancy loss experience. They were abruptly put in the opposite position of being a patient by the loss. Mulé was perplexed by the caregiver’s diversion from her own approach to disclosure of unexpected diagnoses to patients, when she observed, “I work in the healthcare system myself and I deliver bad news every day. Didn’t they know that the brain’s memory center shuts down when people are stressed?” Receiving care as opposed to being the care provider was an added source of tension for Carle when she described her providers’ lack of empathetic responses, “I felt bewildered on the receiving end of the healthcare system. Its personnel and processes felt cold and harsh when I most longed for compassionate care and deep human kindness.” Cotter explained how her dissatisfying experience was a reflection upon her profession and a unique addition to the trauma of her loss, “I felt disillusioned leaving these medical appointments, embarrassed for my own profession, and alone without medical providers who I could trust to guide me.”

Some of the experiences with care providers and professionals invoked shame and self-reproach. Faison reflected upon how the discomfoting words that afflicted her aligned with her previous perceptions about comforting language and was a source of her own culpability. She confessed, “[The doctor’s comment about conceiving again] was literally the last thing I wanted or needed to hear. Certainly, looking back, in any other circumstance with me not being the patient, I would have thought those words were expressing empathy and hope.” She also described her personal struggles caring for patients with more favorable outcomes when she returned to work after her pregnancy loss, “I hated [my patient] for having a cute little baby. I hated myself for having these thoughts, which would continue in the subsequent months as I saw healthy babies and pregnant mothers—inescapable reminders of the unattainable, the absent.” Ciacco was dismayed that her care-providing contributions after her loss didn’t facilitate closure to her perinatal grief experience as she hoped, admitting, “I thought that being the chaplain to a mom who experienced stillbirth would be a pivotal moment in my life. . . . I felt grateful, humbled, and sad, but I didn’t feel like this was the end. There was more to my journey. Somehow, there is more of me than just the death of my child.”

### Recommendations for Future Research

An analysis of the reflections and narratives from the five stories that were composed by healthcare professionals invoked a novel viewpoint of pregnancy loss and grief that could serve as an impetus for improvement in care provision. When professional caregivers are dissatisfied and even traumatized by care they previously perceived as the standard, it points to the necessity for reevaluation of the current norms, increased research, and enhancement in education and professional development. Advancement in communication skills through simulation is an area that allows caregiving professionals to hone their approaches to conveying empathy in bereavement situations and should be evaluated and offered more frequently in both

primary and continuing learning environments. Realization of a pattern of professional error and shame for occupational affiliation may also be another aspect of ontological death for healthcare providers experiencing perinatal loss and suggests further research is needed.

## Conclusions

Responses to loss often originate from implicit beliefs about the nature of the loss and grief rather than evidence taken from emerging grief literature or a thoughtful inquiry as to what the patient is actually experiencing (Bute & Brann, 2020) (Bute & Brann, 2020). When patients experience the anguish of the loss of their longed-for child and comforting communication is withheld (for fear of saying the wrong thing or lack of training in empathetic responses), the grief experience can be unnecessarily complicated or prolonged. Heartfelt, compassionate, trauma-informed, and evidence-based care can adequately frame the grief experience and foster an emotionally healing trajectory (Evans, 2021). In a moment of solace and embraced by her supportive colleague, Ciaccio recollected, “In that moment, I am held. I am held by the nurse, all other moms who lost their children, my chaplain friends, my supervisor, and by God.” With adequate training and support, professional caregivers can learn to integrate gentle, systematic, effective, and compassionate approaches to grief, and those enduring it can begin healing.

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## Commentary

# Miscarriage: The Pain of Unacknowledged Loss

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**Conflicts of Interest.** The author reports no conflicts of interest.

**Abstract.** These stories of fetal death make us aware of the several losses that attend a miscarriage and—equally important—they highlight the personal, cultural, and organizational constraints that make difficult the kind of caring responses needed to address these losses. In reading these narratives, we feel the grief and frustration caused by the inappropriate, or absent, reactions of caregivers. The seeming meaninglessness of the event led some to look for meaning in religion, while for others, the loss challenged their understandings of God. These stories also point to the importance of rituals—religious or otherwise—for helping the bereaved “carry their sorrow.” Careful listening to the experiences of these women can help us make the changes—organizational and personal—that are necessary to provide the care and comfort those living through a miscarriage need.

**Keywords.** Miscarriage, Pregnancy loss, Narratives, Bioethics, Empathy, Bereavement, Obstetrics

## Introduction

These stories are difficult to read. In recounting their experiences of miscarriage, these twelve women share the grief, guilt, loneliness, and anger that accompany their loss. We learn of the complicated emotions and reactions that come with the loss of a child not yet born. A miscarriage is the loss of a pregnancy and a child, yes, but it is also the loss of confidence in one’s ability to parent, of an imagined future, of things hoped for.

The women who write here reflect on these many losses. There is the loss of motherhood:

When my uterus said ‘never mind’ to that first brief pregnancy, the possibility for that baby left my body, but the mother in me had already

taken root . . . I had to let go not only of the baby I had begun to love, but also of my nascent self-concept as a mother.

—Jessica Bratt Carle

There is the loss of the feeling that your womb, your uterus, is a safe place. When Jill Wieber Lens was told (incorrectly) that her miscarriage was the result of the premature separation of the placenta from her uterus, her first thought was that she had deprived her child of oxygen, in her words, “killing him.” She goes on: “my body was the scene of his death. I should have known. I should have protected him.”

There is the loss of connection with others, as described by three different women:

I created distance from people who might ask about my pregnancy while simultaneously



feeling abandoned by my own body. It seemed my body had failed.

–L. Emily Cotter

. . . these losses affected my relationships, work, and life. I changed. We both did. I noticed that our relationships with friends who are having kids also changed.

–Indrè Razbadauskaitė Venskė

When you lose a baby, no one tells you there is more than grief to attend with. When your child dies, a thick and invisible barrier grinds up from the ground that divides you from the rest of the world.

–Shaina Rose Ciaccio

These stories make clear that the losses that accompany a miscarriage are distinct and especially painful. Unlike the death of an older child, the loss of a “not-yet” child puts these women in a social space that others cannot comprehend or adequately respond to. In spite of the fact that between 10 and 25 percent of women in the US who know they are pregnant will have a miscarriage (Dugas & Slane, 2022), we have no script or set of rituals that allow us to respond to this type of untimely death. Even with the cultural weight of our notions of motherhood, there is no widely accepted way to acknowledge pregnancy loss, which creates a unique kind of loneliness.

### Where Are the Caregivers?

It is discomfoting to learn of the often bumbling, awkward, and inappropriate responses of caregivers to a mother’s loss. We see, in these descriptions, how the bureaucracy and hierarchy of medical settings prevent what should be ordinary and important caring reactions to the tragedy of miscarriage. We feel the frustration as Monica Snyder explains her struggle to arrange grief counseling:

Our health insurance provider required that I get assessed before referring me for counseling. At the mental health clinic, the psychiatrist assessing me explained that bereavement isn’t a mental health disorder, and so the clinic couldn’t offer me many resources. . . . She added that it was normal to be upset since it had been only a week since the miscarriage but that it sounded as if I already had a good support system. . . . I

was taken aback by how aggressive I had to be to get help. The referral went through weeks later, but I still wasn’t able to see the counselor I chose because she required an authorization number from my insurance provider. . . . The entire process took months of persistence, all when I was already psychologically exhausted.

The way we organize hospitals and the caring professions creates unnecessary disquiet for mothers-to-be, as in this case where, in the course of a 13-week ultrasound, a technician casually informs Snyder that she is carrying twins, something her OB had not noticed:

During the test, the technician asked if I was aware I had a twin pregnancy. I was not. My OB had told me this was a singleton pregnancy. The technician explained that there had been a twin who passed away, probably around the 6-week mark, and that my body would reabsorb the remains of the twin . . . I was surprised at the intensity of my grief.

Nurses often feel that they are not in the position to break bad news, resulting in moments of anxiety. Two women describe these situations:

When the nurses put the monitors on my belly, they couldn’t find his heartbeat. I remember them getting more nurses to try. At some point, they stopped trying. But no one said it out loud. I remember when all the nurses later rushed back in when I started screaming, processing the fact that Caleb had died in my belly only weeks before his due date. Hours later, an ultrasound confirmed what was already obvious.

–Jill Wieber Lens

As the nurse tried to hook me up to the fetal monitoring machine, she struggled to find a heartbeat. After several minutes, she left the room to get help from the nurse practitioner. “She doesn’t know what she’s doing,” I thought to myself. When the nurse practitioner couldn’t find the heartbeat either, she left the room to grab a different doppler machine. When that proved fruitless, I told her, “This is bizarre. Dr. M always gets it on the very first try.” She told me that I would need to go to the hospital for an ultrasound to check on the baby.

–Angela Yvonne Dahm

While their position in the medical hierarchy may limit what nurses can share with patients, it provides them with the freedom to go beyond mere

medical treatment, allowing them to look after the social, emotional, and spiritual needs of women in their care. Nurses become “angels.” When Christina Mulé was going through a miscarriage, her husband, John, was told he could not be with her, but “A nurse-angel, Chris, who had come back to nursing after retirement, figured it out! John was given a new badge and explicit instructions not to wander the hospital floors.” Angela Yvonne Dahm was comforted by a nurse who had experienced her own miscarriage:

My baby had been born. He was dead. He was no longer inside of me. He was here. He was gone. Miranda was my nurse that morning and she appeared to be an angel. She told me she had been in my place, in this exact room, and lost twin girls. She mourned with me. I felt the intangible presence of God in our shared humanity.

Unburdened by the strictures of the physician-patient relationship, nurses can offer a loving response to grief. Shaina Rose Ciaccio was told by a nephrologist that her newborn son had a worrisome fluid buildup in one of his kidneys, bringing back the painful memory of her earlier miscarriage. She describes her reaction:

After he left, I picked up my son gently, and suddenly, began to sob uncontrollably. My body shook violently as I clutched my son to my chest. The nurse came in, alarmed at the scene before her. Between heaving breaths, I told her about my first son, and the nephrologist’s news.

Sobbing, I wrenched out, “I can’t go through this again. Do you understand? I can’t lose one more. If I do, I want them to bury me too. I cannot live through this again!”

Between soothing words, she eased onto the bed, her arms wrapped around me and my baby, holding us tightly. A tiny island of grief, anchored in that moment by one touch.

Of course, not all nurses are angels, but it is striking that in these stories, physicians are seldom, if ever, portrayed as comforters. Quite the opposite. Nearly all the women who write here report that their doctors downplayed or glossed over the severity of the loss of a child. In the first narrative, we learn of a mother whose request for a genetic test

of tissue from her fetus was met with resistance by her physician:

To her this was just another miscarriage and just another procedure, but for me, this was my baby and all of our hopes and dreams. I didn’t like her but she was competent and I rolled with it. What choice did I have?

–Christina Mulé

This complaint, “just another miscarriage” is a common thread, as seen in these three accounts:

I could see the doctor’s expression drastically change to a solemn distressed look. Not saying anything, he put down the stethoscope. I earnestly kept asking questions until he finally looked me straight in the eyes. “Your baby may be dead.” Just like that.

–Rose Bendas

The doctor assumed we wanted this nightmare to be over . . . It turns out, this busy doctor was also teaching at a nearby university and had a very busy, full practice of his own. His lack of kindness and impulse to rush us through the process could not have hurt me more. Here I was at the most awful moment of my life and he made that moment worse for me.

–Angela Yvonne Dahm

What made matters worse was when I followed up with my clinician. She made me feel as if I was just another mother who lost a baby, asking what my future plans were for kids, if I wanted birth control, or if I wanted to try again. In my mind, I was screaming, “What I want is my baby that God selfishly took from me! What I want is for you to know that I am hurting and that I am not okay. I am mad, and I am dying inside!” All I could respond with was, “I don’t know what I want to do at this moment” . . . Why was she acting like losing a baby was normal and something she witnessed every day? It wasn’t normal to me, and the hurt was far from any normal hurt that I have ever felt.

–Sirena Washington

I felt bewildered on the receiving end of the healthcare system. Its personnel and processes felt cold and harsh when I most longed for compassionate care and deep human kindness.

–Jessica Bratt Carle

Monika Jaquier, whose baby had anencephaly, was told by her obstetrician that her “pregnancy should not last a day more, that [she] should stop it and

start again with another baby that is worth it." To her, this advice reduced the value of her baby to "no more . . . than an earthworm." She writes, "To my husband and me, she's our beloved daughter, growing and developing in my womb, reacting to our voices. To our children, she's their little sister who will stay for just a short time. To others, she's just worthless."

What emerges as we reflect on these encounters is the desire on the part of physicians to look past the painful loss experienced by these women, to minimize or deny the grief, to encourage them to try again. This is, perhaps, not surprising. In his book, *Power in the Helping Professions*, Guggenbuhl-Craig (2015) explores how the choice to enter a helping profession arises "out of a deep inner need." Viewing helper and client as two poles of one "archetype," he concludes that those who choose a career in helping others are often those who are uncomfortable with weakness, be it manifest in ignorance, disease, or death. They feel threatened and powerless when confronted with the possibility of their own weakness. Turning his attention to doctors, he says:

The doctor [turns] his patient into an object of his power drive. [This is] why the power exercised by the physician makes such a cheap and shabby impression. It is the result of a partial psychological and moral failure by both doctor and patient. The doctor is no longer able to see his own wounds, his own potential for illness; he sees sickness only in the other. He objectifies illness, distances himself from his own weakness, elevates himself and degrades the patient. He becomes powerful through psychological failure rather than through strength. One pole of the archetype is repressed, then projected, then reunited through power.

Seen through this (Jungian) lens, a doctor regards an anencephalic baby as worthless—because there is nothing medicine can offer to heal this child, she serves as a stark and frightening reminder of the caregiver's weakness and limitations.

But it is not just medical caregivers. These stories call attention to the fact that others outside of the medical system often react to news of a miscarriage with "dismissive positivity"—"a cognitive bias, an unconscious mental strategy to avoid often painful,

unresolved, and problematic emotions at all costs" (Rucker, 2020):

I did join pregnancy loss groups online, which helped significantly. However, it was disheartening to see so many grieving women also struggling with profound feelings of isolation. They reported countless comments from friends meant to be comforting but often quite hurtful: "At least it wasn't a real baby." "You can always have another." "At least you know you can get pregnant."

—Monica Snyder

Jill Wieber Lens notes:

[S]pare me the idea that "everything happens for a reason." Nothing can make my child's death justifiable. Nothing can make it okay that he's not here. Nothing can make it okay that I didn't get to celebrate his 5<sup>th</sup> birthday *with* him this summer.

Having more than one miscarriage solicits another version of dismissive positivity:

Like many women, I have suffered numerous miscarriages. After the first, those around you seem to think it is easier to bear the subsequent ones since "You've been through this before." Worse, if you have at least one child, as I did, some may even feel inclined to tell you, "At least you *have* a child," or "At least you know you *can* carry to term," or a whole slew of entirely unhelpful and insensitive comments meant to, I don't know, make you feel better?

—Giulia Faison

In short, caregivers of all types, inside and outside of medicine, find it difficult to face what may appear to them as the ambiguous loss of miscarriage. Mothers are hurting and caregivers are confused. Is there a way to make sense of this loss?

## Religion and Ritual

The search for meaning in this random, meaningless, painful event leads many of the mothers who share their experience of miscarriage to look to religion. At times, that turn involves questioning the role of God in the tragedy:

How could this have happened? Why did this happen to us? Not that I want anyone to experience their child's death, but why us? Why

couldn't medicine prevent this? Why is the medical response to stillbirth at term apparently "this happens"? Why did God let this happen? How could God let a little baby die?

–Jill Wieber Lens

I lost my faith and hated God for not finding me worthy enough to be a mother. I couldn't understand why this was happening to me. I was in the darkest place of my life while a thousand thoughts ran through my mind. I had taken care of everyone else's children most of my life, but God didn't think I would make a good mother. How? Why? This wasn't fair.

–Sirena Washington

In other cases, the turn to religion offers comfort. Monika Jaquier, the mother of the girl born with anencephaly, recounts:

[Her] body was not made to last; we see it with our own eyes. When her breathing becomes slower and slower, we can tell her that we're ready to let her go. She breathes once more and then dies in our arms. Like a candle flame that gently goes out, her soul leaves her body to join her heavenly Father. The experience of her peaceful death will give me comfort and strength in moments of sadness ahead.

Ritual plays a role here, with or without religion, traditionally conceived. Monica Snyder notes the need for, but lack of ritual: "I found myself craving ritual and acknowledgment but not knowing how to fill those needs." Other accounts confirm the value of ritual. Shaina Rose Ciaccio, a chaplain who has suffered a miscarriage herself, describes ministering to a mother who lost her baby:

His mother weeps as I ask permission to baptize him, and she thanks me with her tears. I take out the oil, placing a little dab on his forehead, making the sign of the cross. I pray as I anoint him, blessing his life and his mother . . . I take her hand again and I pray for her that God would feel present to her in her moments of despair . . . With one last hug, through my N95, I kissed her son on his forehead and placed him gently back into his mother's arms. She thanked me profusely for coming in, especially to an isolation room and felt comforted knowing that her son was baptized and her sorrow had been held.

Sorrow can also be held by rituals that have no explicit religious component, as described by Angela

Yvonne Dahm, who talks about the comfort offered by meals that were delivered for two months and by family members who simply sat with her and her partner. Her friends also helped by formally recognizing her loss:

On Theodore's due date, my friend Ariel organized a group of women to walk around our block two times in silence, stopping in front of our home for a brief pause each time. By the end of the walk, my grief felt notably lessened, as if each friend there helped me carry a little bit of the load as we held hands. One of the biggest lessons grief has taught me is that I'm not alone, that social connection can foster healing [ . . . ]

## Responding to Absence

Absence. Absence marks the experience of parents who live through the tragedy of a miscarriage. The absence they feel is made worse by our personal and organizational inability to respond to their loss(es).

Clearly, we who care for those who suffer this cruel loss need to find ways to respond that move beyond glib and hurtful dismissive positivity. Is it possible to acknowledge the pain of a miscarriage while offering words of encouragement? The answer may be found in these oft-quoted words from Julian of Norwich, a 14<sup>th</sup> century Catholic mystic: "All shall be well, and all shall be well, and all manner of thing shall be well" (Julian of Norwich, translated by Barry Windeatt, 2015). This may sound like just another version of dismissive positivity, but there is something deeper here that recognizes that "being well" requires sitting with the loss and eventually finding a way to incorporate that loss into the arc of one's life. L. Emily Cotter, a caregiver herself, offers an example of this way of thinking about, and responding to loss:

Since that time, [I have] a greater appreciation for how little control we have over so many aspects of our lives [ . . . ]. I strive to avoid presumptions about what someone might feel when experiencing adversity, instead re-committing to greet each encounter with curiosity and generous listening. [ . . . ] I am more intentionally making space for these emotions [that come with a miscarriage]: fully embracing them as they arise and letting them fill me with the abundant depth



of loss. [ . . . ] I hold in my heart the anguish of those who have experienced infertility and pregnancy loss. I have grown such deep respect for the strength it takes to try again and find peace in accepting a life that may be markedly different from one's earlier dreams. It may be that our fertility journey is over, or perhaps not. Either way, I will be giving myself grace to embrace the future in whatever way it comes [ . . . ].

In describing the losses in her life, writer Anne Lamott (2022) captures this approach to living with loss:

You will lose someone you can't live without, and your heart will be badly broken, and the bad news is that you never completely get over the loss of your beloved. But this is also the good news. They live forever in your broken heart that doesn't seal back up. And you come through. It's like having a broken leg that never heals perfectly—that still hurts when the weather gets cold, but you learn to dance with the limp.

But we cannot simply wait for the recruitment of a generation of kind, caring, spiritually centered health care providers. If we want women who miscarry to be treated thoughtfully and appropriately, we must rethink the way we organize care. Jessica Bratt Carle, frustrated by the care she received, recognizes that caregivers are caught in a system that does not give them the time and space to be thoughtful and empathic. Talking about her OB, Carle says:

Her affect seemed incongruent with the situation, but I wonder now, what would an affect congruent with the situation even look like for a provider who sees this kind of thing so routinely and is only given 15-minute appointment slots to tend to her patients? Was it unreasonable for me to want her to tend to my emotional state and show anything more than perfunctory empathy? My world had stopped, but hers had to move on to the next billable encounter. In hindsight, I suspect it would have taken a monumental effort for her to pause and adequately respond to me in the way I yearned for.

Carle goes on to offer trenchant observations that all those who manage health care organizations should read and pay attention to:

Healthcare keeps overloading its precious human resources with technology and documentation

and revenue cycles, all in the name of patient satisfaction and safety, and we have become too accustomed to letting that overload undermine the very rich, meaningful human interactions that draw people into healthcare in the first place. What tasks and schedule constraints and efficient workflow processes would my OB have had to ignore to set aside her distraction and be present with my husband and me, even for a few minutes? To acknowledge the pain and shock we were experiencing, to normalize the grief process we were about to embark on, to demonstrate *care*?

## Postscript

In spite of the fact that this short essay is included in the journal, *Narrative Inquiry in Bioethics*, the words “ethics” and “bioethics” do not appear. This may seem curious. One could argue that it is reasonable to exclude the word “ethics” as this is a subfield of philosophy, given to esoteric (but important) argument and not really relevant to the practical matters of caregiving. Must one really be familiar with Aristotle and Heidegger to provide “good” care (in both senses of that word)? But bioethics is an applied discipline, with a focus and direct relevance for the practice of caring. The absence of the term bioethics here implies, and rightfully so, that to provide care that is morally and practically good, one need not always attend to the topics that occupy bioethicists—the balancing of moral principles, algorithms for responding to the scarcity of resources, the complexities of surrogate decision making. While these are important aspects of good care, the demands of practical wisdom require that we attend to the social, organizational, cultural, psychological, and spiritual dimensions of caregiving. A bioethics committed to good care can do no other.

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## Commentary

# Humanizing the Language and Experience of Pregnancy Loss in Health Care

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**Conflicts of Interest.** The author reports no conflicts of interest.

**Abstract.** The experience of pregnancy loss is a relatively common, but seldom discussed event in many families' reproductive years. Accordingly, this occurrence is one of the most common poor outcomes treated in healthcare. The narratives in this issue present several themes shared widely despite a diversity of circumstances in how women and their families experience pregnancy loss. Unfortunately, negative experiences within the healthcare system—with both providers and the process of medical treatment, surfaced as a common theme. These articulated experiences prompt a reflection on how pregnancy loss is perceived, described, and communicated about in medicine. Notably, the stories reflect the outcome of several patterns in medicine that can introduce bias and harm in the patient-physician interaction. First, there are inconsistencies within healthcare of how pregnancy loss is named and defined, and second, there is a sharp distinction in how early and later losses are considered medically. These medical considerations affect the vocabulary medical providers use to describe and discuss pregnancy, pregnancy loss, and its related management. This language, in turn, conveys values, and thus potential depersonalization and bias. These stories echoed a need for acknowledgement of the individual's specific situation through open listening and affirmation of the life lost, however that is defined by the parent. The narratives also prompt a consideration of the need for streamlined and individualized processes for acquiring information, receiving treatment, and memorializing a child after a pregnancy loss.

**Keywords.** Pregnancy Loss, Stillbirth, Miscarriage, Medical Ethics, Narratives

## Introduction

Having children is a highly anticipated life event for many, and brings with it the expectation of love, happiness, and health for a growing family. While the majority of families experience normal pregnancies and healthy deliveries, many suffer, often silently, with pregnancy loss. This issue's narratives give voices to these painful

experiences and explore the grieving process lived by each author. One recurrent theme that contributed negatively to their ordeals was the failure of healthcare providers and the healthcare system to deliver the diagnosis and plan of care in a clear and compassionate way. As a physician who too often must deliver devastating news, and who has lost two early pregnancies, I felt particular discomfort

and sorrow in these indictments. Early pregnancy loss (before 13 weeks completed gestation) is very common, occurring in 10% of recognized pregnancies, but as often as 20% of all pregnancies (American College of Obstetricians Gynecologists' Committee on Practice Bulletins—Gynecology, 2018). Stillbirth (here defined as fetal loss after 20 weeks), is one of the most common adverse pregnancy outcomes, occurring in 1/160 deliveries in the United States (American College of Obstetricians Gynecologists' Committee on Practice Bulletins—Gynecology, 2009, 2020). How can we still struggle so much to find the right vocabulary and implement streamlined systems to help our patients through this tremendous grief?

Pregnancy loss evoked significant emotion resulting in lasting effects for our narrative authors, regardless of gestational age. The deprivation of a life so anticipated reverberates to lost hopes, dreams, existing relationships, and even to identity regarding womanhood and motherhood. Indeed, physicians and nurses are not immune to the bitterness of the diagnosis and its aftermath. Nevertheless, this poignant experience is described by the American College of Obstetricians and Gynecologists as an "adverse pregnancy outcome," lumped in with preeclampsia, growth restriction, and preterm birth (2020). This inadequacy is precisely the issue with medical categorization and vocabulary that this commentary will further illuminate and explore. How these pivotal life events, (diagnoses to medical providers), are categorized and discussed directly impacts words and actions at the bedside. Words communicate value and as such are critical to either harming or healing our patients.

This commentary will focus on themes in this issue's narratives as they relate to the patient experience with the healthcare system and medical providers, specifically. I will contrast patient experiences and delivery of healthcare by illustrating how physicians in particular are trained to consider diagnoses relating to pregnancy loss at different stages. This training influences communications and emotional engagement with patients who are living this experience. The discussion will support recommendations for how medical providers and healthcare systems can improve in providing

compassionate support for those who have suffered pregnancy loss.

### **A Loss is a Loss, no Matter how Small**

Emerging from the narratives is one consistent theme: the magnitude of suffering felt by women after pregnancy loss. Although early and later pregnancy loss differ significantly and are considered quite distinctly by healthcare professionals, the distress patients experienced was surprisingly similar across the spectrum. The authors of narratives describing loss in the first weeks of pregnancy shared many similar sentiments of grief, pain, isolation, anger, confusion, and shock as those who lost pregnancies much later. Indeed, women generally have dreams, expectations, and plans related to family growth that can make alternate paths and outcomes extraordinarily difficult to receive, experience, and accept. Descriptions of the significant and at times conflicting emotions were compelling. Indeed, even women who had not learned a pregnancy existed until weeks after the loss occurred, as in the case of Snyder and her vanishing twin, experienced grief that was "sharp and painful." A central theme from these descriptions is that the degree of these emotions and the processing of the loss is not dependent on the gestational age, size, or manner of the loss. The awareness of a deep and permanent connection to a life begins upon learning of the pregnancy and has lasting effects beyond the loss. As Carle described: "When my uterus said 'never mind' to that first brief pregnancy, the possibility for that baby left my body, but the mother in me had already taken root."

Unfortunately, many also described the isolation, confusion, and hurt resulting from an external tendency to practice comparative judgement: the magnitude of loss and the justification of grief is perceived to be commensurate to gestational age at the time of loss. Carle summarized this distress well: "I still perceived that an earlier loss like mine just wasn't that substantial; not quite as deserving of as much sympathy compared to the kinds of later pregnancy losses and infant losses." This is not a surprising perspective considering some of the comments the authors recalled. Snyder described

having an early loss dismissed as “not a real baby,” and Faison recounts a resident physician’s description during ultrasonography of an early pregnancy as “shmutz.” Similarly, words that shifted focus to hope for the future rather than validation of the current emotional trauma also impeded healing. Even well-intentioned comments like “you will conceive again,” (Faison) “you can always have another,” (Snyder) or even “everything happens for a reason” (Lens) were interpreted as unhelpful or even insulting. Attempts at understanding by projection or presumption of the patient’s sentiments was similarly unhelpful (Cotter). Many found a focus on medical plans, including future pregnancy planning and birth control, to be irritating and mere treatment of a diagnosis rather than an individual (Washington).

The broken-heartedness and the emotions experienced are described as life-changing, affecting relationships, work, life, and self-identity as women and mothers. It is clear from these narratives that those offering support in this context should never normalize or minimize the experience, regardless of when in pregnancy it occurs. As well-intentioned these attempts to ease the pain may be, this is not the support that most authors described as helpful. We must be very careful not to unintentionally (or intentionally) quantify the worth of a child by implying the loss is not as great if it is early, if the family already has healthy children, or if the loss resulted from a terminal diagnosis. As Faison summarizes “A loss is a loss. The value judgment others place on a woman’s loss is not just irrelevant; it is painful, harmful, and helps to irrevocably disjoin the person from her surroundings.” Instead, as many suggested, it is helpful to simply “be with them and hear them out without discounting their feelings” (Bendas). We must truly listen to how women are experiencing their loss, its impact on their lives, and affirm their sentiments without resorting to formulaic responses or projecting our own norms and values.

### The Words We Use Matter

As already alluded to, words impart value and therefore contribute to the positive or negative

perceptions of a patient. Research in other areas of medicine have shown that using pejorative words to describe a patient’s diagnosis (such as the term “sickler” for those with sickle cell disease or “addict” for those with substance use disorders) is associated with negative attitudes toward patients, and however innocent, may contribute to bias and even racism in healthcare (Ashford, Brown, & Curtis, 2018; Glassberg, Tanabe, Richardson, & Debaun, 2013; Power-Hays & McGann, 2020). Characterization of an early loss as insignificant, or a later loss handled without the utmost compassion, communicates a lack of understanding and empathy for the pregnancy’s reality and potentiality in the patient’s life. Statements often meant to provide hope or move a family beyond grief can also be received as indifference or as evidence of a lack of acknowledgment for what was lost. Words are important, and missteps were not lost on this issue’s authors. At times, I cringed imagining these interactions, hoping I never caused such injury. Medical caregivers are trained in delivering bad news and instructed on the importance of empathy and compassion. How could we be so lost in compassionately providing care in these crucial moments? Part of the answer lies in medicine’s confusion and inconsistency of language to diagnose and define these conditions.

As a specialty, obstetricians have been inconsistent in characterizing pregnancy loss. The American College of Obstetricians and Gynecologists, a primary source of practice recommendations, acknowledges there is no consensus on the terminology of early pregnancy loss, and several terms are used interchangeably (2018). Early pregnancy loss is defined as loss before 13 weeks completed gestation, and stillbirth after 20 weeks (between 13 weeks and 20 weeks is unclear, but “miscarriage” suffices). Specifically, only after 20 weeks, or if the gestational age is unknown, beyond a weight of 350 grams, is it suggested to formally report a loss as a fetal death, which implicitly conveys valuation (American College of Obstetricians Gynecologists’ Committee on Practice Bulletins—Gynecology, 2020). Equivocal terminology notwithstanding, certain diagnoses are acknowledged to be more offensive to patients, such as “spontaneous abortion,” “fetal death,” or “fetal demise” (Hutchon

& Cooper, 1998). While focusing on terms may be technically accurate, we must not forget their impact on patients and the risk of distress from the perceived implications. Beyond the role in delivering compassionate, patient-centered healthcare, it bears mentioning that inconsistent terminology leads to imprecision in data collection, ultimately impeding research efforts related to diagnosing and treating pregnancy loss in all demographics.

Medical definitions of pregnancy loss vary by gestational age, as the causes, outcomes, and management are also different. Early loss is considered common and inevitable for some portion of those who can conceive and often spontaneously resolves without medical intervention. The frequency of miscarriage is underscored by medical education and clinical training; in fact, workup is not technically warranted for recurrent pregnancy loss until after three occurrences. Not surprisingly, this is emphasized in our counseling to relieve pain, guilt, and a sense of loss. Although well-intentioned, this approach misses an explicit acknowledgment of the loss, which our narratives reveal, can be monumental even at early gestational ages.

By contrast, for physicians, the emotional impact of stillbirth tends to be experienced, and therefore perceived, as a much greater calamity, as it is potentially preventable insofar as it may result from a maternal or fetal condition or event. Because in many cases, retrospection may suggest an alternative outcome from earlier intervention, this triggers stronger emotional engagement and regret is universal. Potential consequent maternal health risks raise the stakes of management, requiring greater physician involvement, as with induction of labor and delivery. Understandably, as the relationship with a patient and her unborn child naturally advances with time, the impact on a physician grows with gestational age. This is never more poignantly experienced than when hindsight suggests it might have been prevented. These tragedies are scarred in our memories, never to be forgotten. Yet, duty calls and the doleful task of delivering a stillborn in the context of a grieving family is utterly heartbreaking. When faced with death in the delivery room with a mother bereft of her child in the moment

where joyful celebration might have been, even well-trained providers are challenged to respond appropriately.

Another perhaps subconscious reason for our inconsistency is to permit flexibility in the approach to different pregnancy intentions. At identical gestational ages, one moment a physician may be consoling a woman with a “spontaneous abortion,” and at another, providing an “elective abortion.” In the first, the loss is personalized; in the latter, depersonalized, and ambiguities in the medical lexicon admit both. Although inconsistent for those suffering loss (Cameron & Penney, 2005; Hutchon & Cooper, 1998), governing bodies demonstrate deliberate precision regarding terminology in the context of providing abortion services. Physicians are commonly chastised for referring to or documenting an early pregnancy as a “baby” where embryo or fetus is the preferred nomenclature. The narratives in this issue admittedly demonstrate bias in emphasizing the value of even the earliest loss, as those who regard human potential from these early manifestations are more likely to reflect on their loss than those who do not. The language physicians use to describe pregnancy is colored by the circumstances surrounding its desirability or lack thereof, which reveals considerable inconsistency and methodologic inaccuracy. It is beyond the scope of this article to argue for calling an early pregnancy one thing or another; at issue is the awareness of the power of words and their importance in acknowledging pregnancy insofar as the patient understands its implications and eventualities. This judicious use of language will help healthcare providers avoid further wounding a person experiencing this potentially life-changing event and aids in healing after a loss. Although the diagnoses may differ, the requisite discretion in delivering care and compassion for the patient is equal for losses at all stages.

### **How Healthcare Can Support Patient-Centered Healing**

Beyond the role that categorization of pregnancy loss can play in our ability to acknowledge and support the unique psychological and emotional



needs of patients, is the institutional climate of healthcare delivery. Protocols for responding to the diagnosis and ensuing medical management are noticeably absent. Several narratives described receiving mixed messages and miscommunications about options for genetic testing, autopsy, and the frustrating process of obtaining remains for burial. Narratives described reluctance on the part of healthcare providers to gather information related to the loss. Especially for early losses, basic information, such as gender, was noted to be helpful. Not only did this aid in formulating an identity to help parents know and remember their loss (Jaquier), but it also provided information to understand the causes and risks of recurrence. Snyder described her difficult journey to avail herself of the desired medical evaluation, feeling “thwarted” at several points in her healthcare experience by inconsistent messages and the need to advocate persistently for services that should have been more readily offered. An understanding that “pregnancy loss may be an emotional and psychological crisis, even if not a physical one (Snyder)” is warranted. For these needs, a streamlined presentation of various medical options for investigation and treatment is crucial at the time of diagnosis. Diagnostic studies of remains, as well as their return to parents, offer a meaningful “physical testament to this child’s existence” and a source of comfort and closure. For those pregnancies with life-limiting prenatal diagnoses, perinatal palliative care similarly affirmed the child and the parents. This approach coordinated the interdisciplinary services required to offer peaceful and memorable moments together after birth, however limited by time. Outside of empathetic medical diagnosis, treatment, and follow-up, the narratives described various activities that helped in healing, including online and in-person support groups, individual counseling, meditation, and various rituals to memorialize the deceased. Such activities should be encouraged, and a list of local resources should be provided to support an individualized healing journey.

Pregnancy loss is commonly encountered in obstetrics. Streamlining systems to facilitate medical care in response to pregnancy loss are crucial. To

prepare for these unfamiliar and uncomfortable situations, healthcare providers should know what is frequently helpful to patients for remembrance and grieving. Inconsistent advice and unclear processes can add frustration and regret to an already difficult experience. Well-established institutional pathways for choices regarding genetic testing, autopsy, and the return of remains for cremation or burial enables parents who experience pregnancy loss to focus on affirmation of how the life lost matters and that the patients themselves matter as parents (Washington). These unique perspectives benefit from intentional and tailored ways of presenting information and resources to help heal, and healthcare providers must acknowledge this by recommitting in each instance to “greet each encounter with curiosity and generous listening” (Cotter). Seek understanding, affirm their thoughts, and guide them through the choices to be made.

### **Individualized Empathy in the Present and Future**

To truly affirm we care for women who have suffered any pregnancy loss entails fighting for the health of future pregnancies and doing everything possible to prevent recurrence. The etiologies of early and later pregnancy loss vary; some are amenable to risk reduction while others are not. Adding to this challenge is insufficient medical evaluation or an inconclusive investigation. Follow-up is key to continuing the grieving process and this should include gathering all information desired and possible to obtain. As highlighted by Lens, more can be done to reduce stillbirth rates and recurrence of stillbirth. Understanding the circumstances of the previous loss is crucial for future pregnancy care and decreasing recurrence risk (Reddy, 2010). In addition, good counseling regarding the timing of subsequent conception can be the difference between being able to achieve pregnancy or not. One physician’s narrative highlighted an instance of receiving incorrect medical advice that did not consider her age nor her pregnancy desires (Cotter). Indeed, although older data and the World Health Organization (WHO) recommend an interval of

6 months to one year following a miscarriage or stillbirth prior to attempting to conceive, more recent studies indicate an interpregnancy interval less than three months after a loss may actually optimize chances of avoiding another miscarriage (Klebanoff, 2019; Sundermann, Hartmann, Jones, Torstenson, & Velez Edwards, 2017). It is imperative that physicians take these situations seriously enough to maintain clear knowledge of evidence-based medical recommendations.

## Conclusion

This issue's narratives show the intensity of anguish and grief that overwhelm many families who encounter pregnancy loss. Beyond the many tears of our writers and readers alike, the stories validate many who are silent but who have suffered pregnancy loss without permission to feel the loss, process it, and heal from it. Furthermore, the rich details of the narratives contribute significant understanding of the experience for community members and healthcare workers to help them understand ways to support and alleviate the pain of those living the experience. Their heartbreaking descriptions brought into focus the inconsistency and objectivity that often plagues the practice of medicine which demands focus, listening, and compassion. As Jaquier astutely stated: "the wound in my heart their death made didn't close alone . . . I needed to value their existence, as short as it was, and to face the pain of their loss before I could let them go. It is not too late to do this, and I realise it sets me free" (Jaquier). May we all do our part to contribute to healing and preventing future wounds.

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