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PERSPECTIVES

Improving care for women who have experienced stillbirth

Think of the current standard of care and do the opposite

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One of hardest parts of being an obstetrician is taking care of patients who experience a stillbirth. I am very comfortable with the care of a grieving patient and I always have been, although I am not sure why. I have a model of care that I have evolved in my 16 years since medical school graduation. This model is not based on formal instruction because I received none, but on my natural instincts of what a grieving mom and her family need to hear and receive in the worst moments of their lives. All obstetrics providers grieve the loss of the baby, but often not with the patient but on our own. We may do this because we want to respect the patient's privacy or because we are not sure of the words to say. I hope I can provide some guidance for those who struggle with what to do.

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I delivered my first stillborn baby as a third-year medical student. My mentor, a chief resident, saw something in me and encouraged me to care for this mother. She had twins and one baby was still living, but the prognosis was poor since this was the surviving twin from a monochorionic diamniotic pregnancy. On the day of the mom's induction, I just pulled up a chair and talked with her. We talked about her life, the loss of the first baby several weeks before, and her hope that her surviving son would be okay. She felt so bonded to me that she refused to push until I was there. Her delivery is still firm in my mind. I still remember 17 years later the room she delivered in.

My first loss (stillbirth) as a resident was my intern year – a beautiful baby named Jude, who was stillborn at 39 weeks. After delivering Jude, I asked the family about the funeral arrangements. Three days later, I attended his funeral. I looked all around for the mother's attending doctors but none of them were there. I remember thinking then that it was a given that they would be there,

but now I know that it is rare. I also learned a lot about the grief a stillborn baby brings while listening to Jude's father's eulogy. He talked about how Jude would never bake cookies with Aunt Jane, ride the slide with cousin Chris, or put on a yellow backpack and ride the bus on the first day of school. Because of this eulogy, I understood this unique kind of grief that these losses bring early in my training.

I delivered many losses in my residency. The attendings left soon after the birth and I stayed behind with the family. I sat and counseled the families, and I helped them make memories. I realized that to care for these patients, I would need to trust my instincts because there was no formal and little informal training on how to care for families who lost their babies.

Once I completed residency, I was really able to do my "thing." At loss deliveries, I was able to model for residents my method of care. I showed them that families want and need attention, support, and guidance. I modeled for them how to deliver and greet the baby. That it is not necessary to leave the room right after the birth, and it is okay to grieve and help families meet their babies. I modeled commenting on the baby's features, on who they looked like. I showed how laughing about how the baby has grandma's nose is okay. I showed them that it is okay to ask to hold and get a picture taken with the baby. I showed them that these are the only moments these families will get with their babies, and it is our job to help them do this. The family will have many moments alone in the days and weeks to come. They need our support and guidance. It is a part of being an ob.gyn. to care for families after stillbirths, and we do not want our patients to feel abandoned during this time by those they entrust to care for them.

I also was able to create a model for aftercare. I call my families often after they go home. Sometimes I catch them in the anger stage of the grief process and I let them vent. I work through this with them, and I answer their hardest and sometimes accusatory questions regarding care leading up to the diagnosis. I am not saying this is easy for me or for them. I think fear of these tough conversations is a barrier to giving the emotional support that these families need. I work through this with them in an honest and open manner. I also call to check on the patients as much as possible, especially on anniversaries. I am not saying that all providers must follow this model. This is my passion and is natural for me, but data clearly show that the standard of emotional care we provide is not what patients need at this time. Thankfully, there is an amazing resource of grief counselors, social workers, online resources, and support groups for these families to help them get through the tragedy. These resources, however, are not the provider who spent this precious time with them and their beloved baby, and our emotional support is invaluable.

This past year has been very eventful for me. One of my patients delivered a new baby, after a prior loss, and asked if we could teach together. I had mentioned that everything I do with stillbirths is not based on my residency education, but on my experience and instinctual feeling of what families need. She knew from friends in bereavement circles that they felt that their care was different. We started teaching last summer and have done 10 training sessions to date; hopefully we will continue to teach new groups of nurses, residents, medical students, doulas, and physician assistant students each year.

This year also was eventful because I discovered the Star Legacy Foundation, a national not-for-profit organization with the goal of spreading awareness, education, and prevention regarding stillbirth. I attended their 2019 Summit in Minnesota. I thought I would meet many more doctors and midwives like myself, and I would learn even more about care for bereaved patients. However, that summer I learned preventing stillbirth may be possible from the then chief medical officer of Scotland, Catherine Calderwood, MB ChB. She talked about the preventive protocol she had created that had reduced the stillbirth rate by 23%. Because I was one of only five ob.gyn. nonspeaker attendees in a room of 400, I realized I had a real opportunity to try to bring some model for prevention to the United States. I brought the U.K. protocol to my practice and we have been doing it now for 9 months. (See "Decreased fetal movement: Time to educate patients and ourselves" <https://www.mdedge.com/obgyn/article/221372/obstetrics/decreased-fetal-movement-time-educate-patients-and-ourselves> at mdedge.com/pediatrics.)

I have had a year to think about why the U.S. stillbirth rate is higher than that of many high-income nations and why we have the lowest annual rate of reduction in the 2016 Lancet series among high resource nations.[1] I think it is due to lack of education and training for providers in stillbirth prevention and care, which has led to further marginalization and stigmatization of bereaved moms. This has pushed them further into the shadows and makes it taboo to share their stories. It is providers being fearful to even mention to patients that stillbirth still happens. It is the lack of any protocol on how to educate patients and providers about fetal movement, and what to do if pregnant women complain about a decrease or change in fetal movement. I think a lot of this stems from an innate discomfort that obstetric providers have in the care of these patients. That if women felt cared for and empowered to tell their stories, there would be more efforts at stillbirth education and prevention.

I often think of an experience that the founder of Star Legacy, Lindsey Wimmer, experienced when she lost her son, Garrett, 16 years ago. She told a story in the documentary, "Don't talk about the baby." She tells that on the first night of the induction, the nurse came in and told her that the attending wanted to turn off the oxytocin so "she could get her rest." I heard this and immediately

knew the attending's true reason for turning off the oxytocin. Lindsey then said she knew it was because the attending did not want to wake up to deliver a dead baby. I wrote Lindsey that day and told her I completely agreed and apologized on behalf of my profession for that care. She wrote me back that she had waited 16 years to have a provider validate her feelings about this. I told her I think her doctor was fearful and uncomfortable with this birth and was avoiding it, but I believe with better education and training this can change. I want to deliver babies like Garrett during my shift, because it is giving this vital care that reminds me why I became a doctor in the first place.

Dr. Heather Florescue

I know there are many providers out there who follow a similar model, but I want more providers to do so, and so does the bereavement community. In one study of 20 parents, all but 2 were frustrated about how the ob.gyn. and staff handled their deliveries.[2] I truly believe that every person who delivers babies does it because they love it. Part of doing this job we love is realizing there will be times of great sadness. I also believe if this model of care is attempted by wary providers, they will quickly realize that this is what patients and their families need. With this care, stillbirth may become less of a taboo subject, and our stillbirth rate may fall.

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