NARRATIVE
ESSAYS

"I'm Sticking With You, Doc"

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In the summer of 2012, I scanned through my schedule and noticed an unfamiliar name. Terri was a new patient establishing care. I met with Terri, a registered nurse, who wanted to discuss polycystic ovarian syndrome and her future fertility.

I placed her on Glucophage and medroxyprogesterone, and scheduled follow-up visits. She declined contraception and preconception care counseling. She'd been in a monogamous relationship for years with no protection and has not conceived yet. She was not hopeful that pregnancy was on the horizon.

In the fall of 2015, Terri came in concerned about being late. Although not unusual considering her diagnosis of irregular periods, we did a pregnancy test. Sure enough, the test was positive. Terri was excited, and we gleefully initiated her prenatal intake and subsequent follow-up visits. Her pregnancy progressed wonderfully until week 18. Terri had presented for a routine fetal survey. I don't often receive pages from the maternal fetal medicine (MFM) attending, so I immediately started to worry when I received one that day. The message staring back at me read "Fetus with possible hypoplastic left heart disease complicated with aortic and mitral atresia." I was stunned and upset, knowing this was a highly desired pregnancy. I called the MFM attending for more details. We made plans to continue the discussion with Terri and her partner and review future care and options for this gloomy and lethal diagnosis.

Terri was devastated by the news but rallied around quickly and followed up with an avalanche of questions. "What does that mean for my baby? How severe is the left ventricle? Will the baby need surgery in utero? Will the baby make it to term? Should I continue my care with you or see MFM? When can I talk to the surgeon?" Her anguish was palpable and we just held hands pondering where we could go from here. I didn't have answers. We were both heartbroken.

I'm a family physician with surgical obstetric privileges in an academic urban tertiary center with most subspecialties within. Over several weeks, multiple emails and meetings involving pediatric cardiology, MFM, neonatal intensive care unit (NICU), labor and delivery staff, and I as her primary care physician, we came up with a proposal to transfer the newborn to Children's Hospital for possible immediate surgical intervention. Terri met with the chief of cardiothoracic surgery at Children's and allied social workers with years of experience working with parents of children with complicated medical issues. My patient got full briefings and attended most of those meetings. She understood the odds of survival were low and didn't want her baby to go through all the pain of multiple staged surgeries.

With all of the facts and options presented, Terri and her fiancé decided against pregnancy termination. Instead, they chose to continue the pregnancy regardless of the outcome and rejected the recommended transfer of care. They ultimately made the difficult decision to have minimal to no intervention for the baby and accept the outcome. Terri and her partner decided to continue her care with me as her OB provider, announcing "I'm sticking with you, Doc." Needless to say, I was honored but also apprehensive about this role. The complexity of the antenatal diagnosis was unnerving and I was hesitant to accept the responsibility. I felt inept with the expected challenges that would be involved.

Moving forward, we invited neonatal palliation and the ethics committee to weigh in and continued to meet as a team. Working together, we created a birth plan that ensured the parents' desires and goals of care would be respected. The plan included psychosocial, emotional, and spiritual support for the family as well as the staff. Details on Terri's care in labor and support both in the newborn nursery and at home/hospice were clearly outlined as we anticipated that the baby would be discharged

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before his inevitable death. We wanted Terri and her fiancé to be as prepared as possible and feel supported through this difficult process. We frequently revisited these plans.

Terri presented for induction and ended up with a Cesarean section. Having surgical privileges, I did the surgery and handed over the feisty, active male newborn to the NICU team. After an initial evaluation, baby Jo was kept on mom's chest while I anxiously finished the procedure. The parents were overjoyed but also apprehensive. Baby Jo's vigorous cries had a soothing effect in the surgical suite.

As expected, baby Jo had few breathing episodes but Terri was well prepared, informed, and handled these events quite well. Quality time and making memories trumped our needs to complete the newborn check list. I had to accept that the parents required a different kind of care.

On day 4, the family was discharged. Neonatal palliation set up home hospice for baby Jo and the parents were fully apprised of the different possible scenarios. Cyanotic spells and feeding difficulties became more frequent but mom was adamant with continuing with hospice support at home and declining hospital evaluation. Baby Jo passed peacefully on day 8, swaddled in his parents' arms.

As I reflect on this patient's choices, I am amazed by the resilience and fortitude of the parents despite the unavoidable ending. I deeply appreciate the trust and privilege Terri gave me when she chose me as her primary obstetric provider. I felt supported through this process by the multidisciplinary team and Terri felt heard and well advised. I also treasure the wide range of opportunities given to me as a family doctor. Despite the tragic conclusion, the collaboration between the various departments resulted in an acceptable outcome to the parents. Integrating neonatal palliation and the ethics departments was helpful in mitigating both our fears and concerns of substandard care, as well as any dissatisfaction or regret with Terri's care.

I had another opportunity of caring for Terri through her next pregnancy. With baby Ty on her chest, she mouthed silently to me through her tears of gratitude "Jo came back." I was equally grateful and humbled by her confidence in me. She stuck with me indeed.

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