Palliative and Supportive Care

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An arc of life

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Essay/Personal Reflection

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The ultrasound report from 18 weeks' gestation indicated "malformations likely incompatible with life." *Incompatible with life*. That's a far cry from *complications*. According to the report, the fetus had, among other things, small, possibly nonfunctional kidneys, hypoplastic lungs, an anterior abdominal wall with large sections missing (some of the gastrointestinal contents were visibly outside the body), an extremely truncated umbilical cord, and a leg that appeared to be missing entirely.

Maria, the patient in question whom I met during my clerkship on the maternity ward, chose to carry her baby to term even knowing it would have extreme and likely fatal deformities.

Unfortunately, Maria had poorly controlled type 2 diabetes. The diagnosis her gynecologist gave to her fetus was "diabetic embryopathy", a vague term referring to a collection of birth defects that occurs as a result of significant maternal hyperglycemia during early pregnancy. The elevated blood glucose can cause a host of issues stemming from metabolic and biochemical disturbances that affect a fetus' development at the genetic level.

She and her husband were adamant about carrying the baby to term. Reading through her clinical notes, I saw that at nearly every one of her prenatal visits, she had been counseled on aborting the fetus. Her providers overwhelmingly told her that it would be safer and quicker this way; one had specifically noted telling Maria that a mid-trimester termination of pregnancy, when properly performed, is around seven times less risky for the mother's health than continuing a pregnancy to term, even without factoring in the risks of a cesarean delivery.

Not to mention it would avoid the horrific psychological trauma that would quite possibly follow the fetus' quick death after delivery. But not only was this baby the couple's first after attempting to have a child for over a year, they were also uncomfortable with the idea of abortion in general.

While Maria was being admitted for labor management, the residents thronged and dissected her records, quickly reaching a consensus that it would have been vastly better for her if she had gotten a dilation and evacuation to abort the fetus earlier in the pregnancy. Now, they all agreed, the hopeful parents were going to agonize through the pain of a protracted labor and the associated possible complications for a baby we were almost certain would die soon after delivery. Most of the doctors did not attempt to hide their feelings or judgement on the matter; it was obvious that many of the medical professionals profoundly — some vehemently — disagreed with the patient's choice to trial labor.

Around 3 A.M., I was resting at the residents' work area with one eye on a giant monitor depicting the fetal heart rate tracings of all the patients on the floor, when suddenly the tracing of Maria's fetus dipped below 110 beats per minute, before dropping entirely off the chart. I immediately notified the resident nearby.

She shrugged. "I think you just saw the fetus die." Seeing what was probably my shocked expression, she added, "It's also possible the ultrasound transducer slipped out of position. It happens. Let's go check."

She sighed and motioned for me to follow her to the patient's room, where we informed Maria and her husband of the disappearance of the fetus' heart rate from the monitor and offered to try to find its heartbeat manually. After manipulating the handheld Doppler ultrasound device on Maria's abdomen and pelvis for 15 min., we still could not find a heartbeat. That's when Maria told us she was feeling her contractions less and less. A cervical exam revealed that the cervix had not dilated much since we last checked four hours ago.

"I did that more for her," the resident said as we walked back to the work area, "the fetus is probably dead."

"Don't we need to visualize absent cardiac activity with ultrasound to confirm fetal demise?" I asked. The resident agreed and said she'd mention it to the attending.

Soon we were huddled with the other residents and attendings. They discussed management strategies with keen interest, as the situation was something most of them had not encountered previously. Someone suggested that this would make for an intriguing case report. Everyone nodded. The attending proposed to remove the fetus via an intact dilation and evacuation, which accounts for fewer than 0.5% of abortions in the U.S. Someone asked about the feasibility of pulling out the fetus, given the mother's incompletely dilated cervix. The attending replied that we could mechanically collapse the fetus' head, its largest part.

"Of course, we'd need to make sure the fetus is actually dead," she quickly added.

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We went to Maria and offered her the procedure. She unwaveringly refused, and instead asked about the possibility of a cesarean section. This elicited significant frustration from the residents and attendings. Even I knew how ill-advised this was. After all, a C-section, a major surgery that carries significant risks, is customarily reserved for clear indications such as persistent fetal distress or abnormal placental implantation. An elective C-section to remove a stillborn fetus at term, especially for a first-time pregnancy in a mother without medical distress, was largely unheard-of.

Despite our best efforts at convincing them otherwise, Maria and her husband were steadfast in their decision. Resigned, we prepped for the C-section. As I scrubbed in, I was surrounded by residents muttering and shaking their heads in exasperation.

The fetus was removed quickly. As the surgeon lifted it out of the uterus, I could see the intestines twisted in a clump outside the body. The placenta appeared to be stuck to the fetus, which, remarkably, was still alive, although just barely.

The NICU team swaddled him in such a way — with only his rather normal-appearing head exposed — that he could have passed for a healthy newborn. As the surgeons worked to close the incision, the baby was handed to Maria, who, with her husband, cuddled the baby between them. Although they were both shedding tears, they simultaneously appeared calm and at peace. Within 20 min of the delivery — before the surgeons had even finished suturing the subcutaneous tissue — the baby passed away in their arms.

I visited Maria on the postpartum recovery floor the next morning. That's when she told me that she was aware of how "absurd" her choice must have appeared to us, her medical team. "Oh, I could guess what y'all were whispering about the whole time I was here," she remarked, without breaking her gaze out the window. I shifted uncomfortably in chagrin and tried to apologize while explaining that the doctors — with decades of combined experience caring for women whose fetuses are affected with severe, life-threatening abnormalities — were being practical and prudent.

She nodded, then told me why aborting the baby was not an option for her, as doing so would have run counter to her core values. After trying desperately for so long to conceive, going through with the pregnancy and delivery had been the hardest and most painful thing she'd ever done in her life. But she knew unequivocally that aborting it would have been worse. She had formed a bond with the baby even as it was in utero. And eventually, she had been able to meet her baby, to know it (even for a few short minutes), and then to mourn the baby's death fully. To her, what mattered most was that her baby had some semblance of a complete arc of life and death, that in ensuring this she and the father could have the opportunity for closure that otherwise would have proved elusive at best and traumatizingly unreachable at worst.

Judgements about our patients and their values are inevitable. We may possess more medical knowledge than they do, and we may enjoy the expertise that comes with having treated countless patients, and it would be remiss of us we failed to ensure that patients are fully aware of the risks and consequences of their choices. However, as much as it is our duty to assist patients with their decisions, it is they, ultimately, who must live with them. We do not know what experiences will trouble our patients more so than others; we are not experts in the depths of their internal strengths, or the directions of their moral compasses, or the contents of their nightmares.

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