
By Jamie Wells, M.D. — October 26, 2017

A case report of 22-month-old conjoined twins evaluated and operated on last year at Massachusetts General Hospital was published in today’s New England Journal of Medicine [2] (NEJM). The staff and family faced impossible choices that prompted involvement of a bioethics committee before rendering such an irreversible decision.

Due to the complexity of the twins abdominal and pelvic connections, doing nothing would have inevitably resulted in their demise. While intervening would facilitate the process for the more challenged one already at imminent risk of dying, it posed the best hope for the stronger, more independent twin. But, held no guarantees.

Before talking about the details of this scenario and the 14-hour surgery performed, let’s get into some background on the development of such congenital anomalies.

Conjoined twins develop in a number of various ways sometimes being attached at the head, other times via the chest etc. There are situations where one degenerates, stops maturing and becomes parasitic— traditionally under developing, leaving behind vestiges that usually do not function as a properly developed appendage would.

“Parasitic twins” can involve one twin ostensibly vanishing into another where what remains is extra limbs. This is dipygus when legs and pelvic duplications— like extra genitalia— arise. In The Science Behind When Two Fetuses Become One [3], I discuss the successful surgical outcome of a baby boy born in India with two penises and four legs [4]. Fetus in Fetu is a type where the abnormal parasitic twin gets consumed inside of the normally developing twin (who serves as the host). This can be further explored in Ovarian Tumors With Brain Tissue, Teeth Or Hair (Not Unheard Of)
In What Dr. Ben Carson And A Baby Girl With 4 Legs And 2 Spines Have In Common, I discuss the recent case of a ten month-old baby girl – called Dominique – born with two spines and four legs traveled from the Ivory Coast to Chicago to cross paths with a team of caregivers who would successfully operate on her in a six-hour surgery. The coordinated effort required five surgeons and fifty clinicians.

Our current Secretary of Housing and Urban Development (HUD), Dr. Ben Carson was a pioneer in the field of pediatric neurosurgery catapulting his world-renowned status in that arena when he was the principal surgeon in a 22-hour operation separating conjoined twins who were attached at the head. This one case alone requires the ability to captain a ship and thrive under the most intense and highly stressful of circumstances. The patient is put in hypothermic and circulatory arrest which have time limits or points of no return. Another such case took him 28 hours where the twins were attached at the top of the head instead of the back and the outcome successfully allowed them to remain neurologically intact. These types of cases do not have roadmaps from a textbook and were groundbreaking for Dr. Carson, the field of neurosurgery and Johns Hopkins School of Medicine.

What was the clinical status of these twins?

The twins were born via spontaneous vaginal delivery in East Africa. Through efforts of a non-profit organization, care was sought in the United States at Massachusetts General Hospital due to the complex nature of the separation required.

They were united from the bottom tip of the sternum (or xyphoid) down to the pelvis in a position that compelled them to face one another. Unable to stand, they were in a lying down position at baseline.

The twin who died as expected in surgery was surviving off of the circulation of the other as her heart and lung systems had innumerable, complicated anomalies. She was less vigorous and cyanotic, in general, since she maintained lower oxygen levels than her sister due to her more compromised state.

Each had a dominant kidney that used the same bladder as a reservoir. Additionally, they shared one liver. They had four arms and three legs. There was one anus along with a nearby tiny opening that reflected a duplication. And so on.

While the twins were being comprehensively evaluated by the various specialists necessary for such a separation surgery, the more compromised twin fell ill prompting two extended stays in the pediatric intensive care unit. Her respiratory distress, recurrent pneumonia and extremely low levels of oxygen in the blood (or hypoxemia) underscored her condition was in decline.

The big dilemma of many...

Operating on her to correct her underlying deficits, while still attached to her twin, would have imperiled her sister. Allowing her condition to run its course would result in her death which if still conjoined would expedite the death of her sibling. Separating the two would guarantee the death...
of one and could save the life of the other—-but, could also put both at risk.

**Bioethics determination…**

The pediatric bioethics committee became involved for many reasons. Their role included consideration of the individual toddler’s rights, the parents’ rights and the medical staff’s rights.

The first thing they determined was the conjoined twins represented two people given they had two brains and two spinal cords. As previously addressed, these situations can arise along a spectrum. They elucidated the team had the acumen to attempt the procedure but were clear there was no certainty with the result. If you have an opportunity to do so, then I recommend reviewing the discussion of ethics section in this publication [2] to appreciate the intricacies of their decision-making. The dominant question being: “Is it ever morally acceptable to sacrifice one over another?”

They did not believe there was a basis for a mandatory separation given the profound influence of “culture and values” in these types of excruciating circumstances. They concluded that surgery should be offered as long as the parents fully understood the risks and benefits and were provided “religious and social support.” They went on to state medical staff who felt participating conflicted with their values should be able to recuse themselves and with support.

**What happened?**

The case was performed. The twin at grave risk passed away as expected in the surgery. Her sister is reportedly thriving.

**Note(s):**

The photo accompanying this piece at the top of the article is not from the case discussed. As you can tell in the x-ray picture of conjoined twins there are fundamental differences, for one, there are four legs.