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No
Surgery to Correct Craniosynostosis

Three months after I was born, my parents brought me into Children’s Hospital where I was diagnosed with a condition called craniosynostosis, a birth defect that fuses one of the sutures—spaces between the plates in an infant’s skull. Without surgery, my skull would have put pressure on my brain instead of the skull expanding normally as my brain developed.¹ I had the traditional procedure called calvarial vault remodeling, where the surgeons make a large ear to ear incision on the scalp and cut the skull to remodel its shape.¹ This approach takes about 3-6 hours² and involves a large amount of blood loss.¹ I was lucky to have many people, including my dad and grandmother, donate blood to keep me alive. Now parents have a choice of procedures including an endoscopic surgery which uses a drill with a small camera to make fewer incisions than the traditional surgery.¹ If I were born and diagnosed in 2015, endoscopic surgery would be a safer choice because of less blood loss, fewer complications, and reduced parental stress.

At Seattle Children’s Hospital, surgeons waited years to start offering the endoscopic surgery to make sure it was safe for their patients.³ Assistant Professor Dr. Emily Gallagher at the Seattle Children’s Hospital Craniofacial Department explained the process to me: “At our center, the surgeons did not jump on the bandwagon to start offering endoscopic surgery, but decided to wait until there was enough valid data to show this was a good option for patients.”³ Seattle Children’s Hospital stayed with the traditional procedure because initially they saw failed endoscopic surgeries were leading to repeat surgeries. Based on years of clinical trial research, Children’s Hospital began offering the endoscopic procedure for any single-suture synostosis in January 2015.³

From 1999 to 2007, craniofacial doctors at Madrid Children’s Hospital conducted a study on 330 consecutive procedures categorized into twelve different types of surgery to compare outcomes. The endoscopic surgery had the least complications of the twelve categories of procedures. The
traditional surgery showed the most complications. This Madrid study helped determine which surgeries are most safe and effective.

From 2003 to 2010, St. Louis Children’s Hospital conducted a study comparing the benefits and drawbacks of the traditional and endoscopic procedures. The 47 infants who had the endoscopic surgery lost 29ml of blood on average. However, 42 patients that had the traditional surgery lost an average of 218ml of blood. The endoscopic surgery is safer in part because it doesn’t require as much blood transfusion as the traditional surgery.

Hospitals have been putting more effort toward studies about how to understand impact on patient’s families. The American Society of Maxillofacial Surgeons conducted a study to compare parent stress levels with each surgical option. Twenty-five parents chose the traditional procedure, and 22 chose the endoscopic surgery. Stress levels were measured in PSI-SF, a measurement of stress in parents of children 1-12 months old. The study showed that parental stress was lower with the endoscopic surgery than with the traditional procedure. Reduced parental stress is another benefit of the endoscopic surgery for craniosynostosis.

If I were born and diagnosed in the year of 2015, my parents would have more good choices of surgeries. Biomedical researchers, like Dr. Emily Gallagher, continue to research ways to improve outcomes and family care for patients like me. Thanks to new studies she’s designing now, she may be able to reassure families that the rate of headaches in postoperative patients is no higher than the general population, avoiding unnecessary stress and expensive, time-consuming trips to see the doctor. Biomedical research is helping families like mine live happier and healthier lives, proving new procedures are safe and effective, and addressing the impact on the whole family. It’s unbelievable how many discoveries have been made about the treatment of craniosynostosis during the short time I’ve been alive.
Reflective Paragraph

When I started this project, the first thing that struck me was how scary it must have been for my parents. As I researched more, I realized how expensive the surgery is, and I started to think about families who can’t afford the surgery or don’t have a hospital near them. The worst of all would be if a parent knew their child needed the surgery, but couldn’t get it for them; or if a person is diagnosed with craniosynostosis too old, the surgery isn’t possible.

As I learned more about the effort that goes into biomedical research that makes treatments safe, I started to feel more grateful for all my medical care from flu shots to surgery. The public should be aware of scientific research so they can figure out when treatment is most likely needed and appreciate the health care they receive. By making biomedical research widely available and easy to understand, doctors and families will have the best chance of getting treatment for people who need it no matter where they are.

Bibliography


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