

Child's case raises questions about tonsillectomies to treat sleep apnea

December 23 2013, by Matthias Gafni

Tonsillectomies fell out of favor in the 1980s, but the procedure has become more common again to treat a new diagnosis - sleep apnea, a breathing disorder - but not without controversy. And the surgery is sure to attract renewed scrutiny because of 13-year-old Jahi McMath of Oakland, Calif., who suffered sudden bleeding from her nose and mouth and cardiac arrest after a Dec. 9 surgery intended to help with her sleeping problem.

She has since been declared brain-dead; a judge Friday granted a temporary restraining order preventing the hospital from removing her from a ventilator until at least Monday. Court documents show the hospital performed a tonsillectomy, in addition to other throat and nose tissue removal procedures.

Even before this case, the resurrection of tonsil removal surgery has spurred debate in the medical world. While some medical experts say the procedure is the most effective treatment for pediatric [sleep apnea](#), others say there is a dearth of studies confirming that. One pediatrician has called the jump in procedures an "epidemic" and a "national embarrassment."

Dr. David Goodman, professor of pediatrics at Dartmouth's school of medicine, is a leading critic of tonsillectomies, and points to Jahi's case as an illustration of the problem.

"What gives me concern is she's a 13-year-old child, and that's an

example of the population we know virtually nothing about (concerning) the value of the procedure," Goodman said. "It doesn't mean it's not valuable, but we know nothing about it."

There's been only one randomized clinical trial studying the use of tonsillectomies in treating [sleep disorders](#), but Goodman said it looked only at children ages 5 to 9.

"I would describe it as a national embarrassment that with over a half century of having tonsillectomies often used, it's irrational that we still don't have high-quality evidence that children benefit from the procedure," he said.

Between 1915 and the 1960s, tonsillectomies were the most common surgery in the United States, done largely to treat chronic throat infections, according to an American Academy of Otolaryngology report on the procedure.

Between 1977 and 1989, such surgeries dropped by half after it was determined they had limited success in treating throat infections. But tonsillectomies have resurged in the past three decades for treatment of sleep apnea.

About 530,000 children under 15 have the procedure annually, according to the study, about 90 percent of them for treating sleep apnea. The surgery rose 74 percent between 1996 and 2006, according to the academy, which represents 12,000 ear, nose and throat surgeons.

Dr. David Tunkel, director of pediatric otolaryngology at Johns Hopkins, says studies show a "benefit for most children, but not for all."

"Often it's the first step in trying to improve the severity of breathing problems," he said. "But tonsillectomies have been under scrutiny for

decades."

Tonsils, the glandular tissue behind the nose, relax along with other throat muscles during sleep, which can affect breathing, Tunkel said. The removal of the tonsils and adenoids can clear breathing passageways.

"A growing body of evidence indicates that tonsillectomy is an effective treatment" for sleep apnea, concludes the American Academy of Otolaryngology guidelines released in 2011, the first official recommendations on tonsillectomy published in the U.S. In addition, children have trouble tolerating CPAPs, or continuous positive airway pressure masks, often worn by adults to treat sleep apnea.

Only 1 to 4 percent of children have sleep apnea, according to the study, but 30 to 40 percent of those children exhibit behavioral problems that can affect school performance. Jahi McMath suffered one of the most common complications of the procedure, according to the report - primary or secondary hemorrhages that occur in 2 to 3 percent of cases.

Deaths are rare, according to studies, with mortality rates between 1 in 16,000 to 1 in 35,000 in the 1970s (there are no current estimates). With more than a half million procedures each year, the odds point to occasional deaths.

"There will be mortalities each year in the country for this operation," Tunkel said.

Goodman called the surgery spike a "unique American phenomenon," and not a good one.

"It's worth noting there are virtually no tonsillectomies done for sleep apnea in England," he said.

"The quality of diagnoses are generally poor and we know little about the benefits, but it's the most common procedure under general anesthesia in the United States for kids-that's not a good combination," he said. "It gained traction at a high level without any good evidence that it's helpful."

AAO released a second set of guidelines in 2011 directing physicians to refer patients to pre-tonsillectomy sleep studies in certain cases, including for obese children. Goodman goes further in his recommendations for tonsil surgeries for sleep apnea patients.

"It should only be done in patients who've had a formal sleep study," he said.

The report found that only about 10 percent of children received such a sleep study before of surgery, largely due to cost, accessibility and varied interpretations of results. Jahi's uncle said she received a sleep study in advance of her surgery.

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