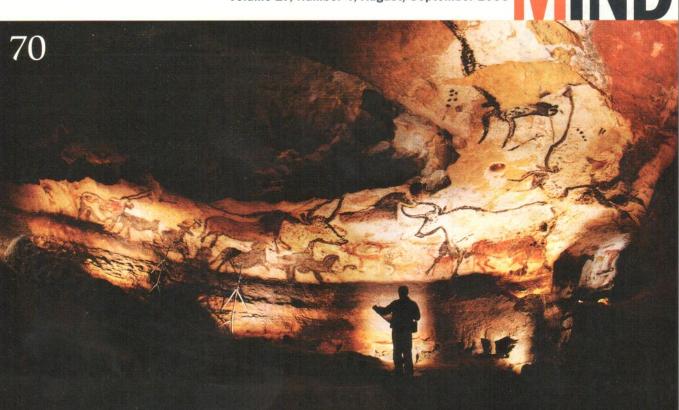
HOW BRAIN CELLS COME TO ATTENTION SCIENTIFIC AMERICAN **A Switch That Shuts Off Depression** page 26 THOUGHT • IDEAS • BRAIN SCIENCE August/September 2006 The BRAIN Science reveals the ongoing changes underlying behavior page 20 Natural High **Diversity's** Surprising Effects Rise of the **Modern Mind** Violence and Pride **Power of Fainting CANADA \$7.95** 

SCIENTIFIC AMERICAN
Volume 17, Number 4, August/September 2006



#### FEATURES

20» The Teen Brain, Hard at Work

Under challenging conditions, adolescents may assess and react less efficiently than adults. BY LESLIE SABBAGH

26» Turning Off Depression

Helen Mayberg may have found the switch that lifts depression—and shined a light on the real link between thought and emotion. BY DAVID DOBBS

32» Diversity at Work

"Diversity" in employee teams does not always equal superior performance. BY ELIZABETH MANNIX AND MARGARET A. NEALE

40 Should We Operate?

How a brain surgeon evaluates the risk of a procedure and informs her patients about it can be as tricky as the surgery itself. BY KATRINA FIRLIK

46» Coming to Attention

Neuroscientists explain how the brain actively selects a target on which to focus. BY ANDREAS K. ENGEL, STEFAN DEBENER AND CORNELIA KRANCZIOCH

54  $^{\circ}$  Violent Pride

Do people turn violent because of self-hate or self-love?

BY ROY F. BAUMEISTER

60» Natural High

The brain produces its own marijuanalike chemicals to protect neurons, and researchers hope to exploit these compounds to ease anxiety, obesity and addiction. BY ULRICH KRAFT



## SHOULD WE

HOW A BRAIN SURGEON ASSESSES THE RISK OF
A PROCEDURE, AND INFORMS HER PATIENT ABOUT IT,
CAN BE AS TRICKY AS THE SURGERY ITSELF BY KATRINA FIRLIK

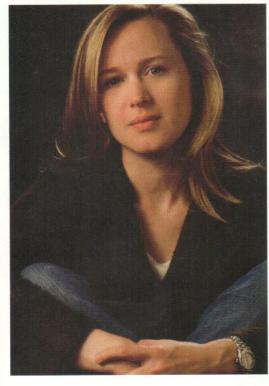
never even met one of the patients who had the most enduring impact on me. I was just a fourth-year medical student on rotation with the neuro-surgery service, excited to participate in a cool, complex case. At my level, I would be relegated to scrubbing in and watching. The chief resident made me feel like part of the team, though, by discussing the case with me and granting me the dubious honor of placing a catheter in the patient's bladder, a lowly but necessary task. I also took the initiative to write some orders in the chart based on what I knew the woman would need after surgery. These orders would turn out to be unnecessary.

I learned from my chief resident that the patient, intubated and asleep in front of me, was young—a teenager really—who decided to undergo surgery only after painful deliberation. Years earlier she had been diagnosed with a large malformed tangle of blood vessels in her brain—an arteriovenous malformation, or AVM. Unfortunately, this AVM was of an extreme type—very large and in a very dangerous location. The situation is informally known among neurosurgeons as a "handshake AVM": as the patient walks out of the neurosurgeon's office after a consultation, a handshake is all the surgeon has to offer.

The patient and her parents had lived in fear, never knowing if or when this malformation would decide to bleed. They knew that a bleed could be fatal. They also knew that surgery could be fatal. They respected their doctor's seasoned opinion that surgery wasn't an option for her. They understood his reluctance to risk having his own hand in her death or, worse, her neurological devastation if surgical removal were attempted. The psychology surrounding brain

# OPERATE?

### Individual personality, more than science, can be the driving factor in electing to undergo brain surgery.



Surgeon Firlik: "The risks have to be laid out plain, in the open. A mentor told me that if the patient isn't crying by the time you're done going over the consent form, you haven't done your job."

> surgery can sometimes be as difficult as the mechanics of it, as I must remind myself every day in my practice.

#### Now or Later

A clear example of that psychology is that one surgeon's handshake can become another surgeon's challenge. When this same woman's original neurosurgeon left town to practice elsewhere, she and her parents sought the advice of another physician, one known for both his superlative microsurgical skills and his willingness to take on the most difficult cases. It was unusual for him to turn away a case; on one rare occasion, in advising a patient against surgery, he was rumored to have told her: "You don't need me. You need Jesus Christ."

I suspect the young woman and her parents were impressed by this surgeon's confidence and reputation. Their impression, combined with the chronic unease that arose from doing nothing, must have tipped their decision toward surgery. In essence, a decision like this one comes down to: Do you want to take your risk up front, all at once (surgery), or slowly, over time (wait and watch)? Individual personality, more than science, can be the driving factor in making such a choice.

The operation was a technical tour de force. The AVM, which had probably been there since birth, did not give in easily. It had spent its entire existence within the dark confines of the woman's skull, sharing space with her brain, and her brain had unwittingly accommodated its presence. Although a potential threat to her life, the malformation was a native and natural part of her, not a recent invader.

The surgeon worked for hours, meticulously, under the brightly lit focus of the surgical microscope. He closed off one abnormal blood vessel after another, making sure to interrupt the complex inflow to the beast first, knowing that interrupting its outflow too early could provoke a bloody explosion. The final vessels were closed off and the tangled mass removed. I was surprised by the size of the depression left behind. The woman's head was closed up, and she was wheeled out to recovery.

After witnessing this surgeon's skill with my own eyes, I agreed that his reputation, and even his cockiness, was well deserved. If I needed brain surgery, he would be my surgeon. I thought about how satisfying it must be for him to go out to the family, announce his success and vindicate their most difficult decision. They had put their daughter's life in his hands, and he was able to offer her a life without fear of the malformation. Others had warned strongly against surgery, citing unacceptable risk. The family went ahead anyway and could now be grateful that they had made the right decision.

The patient woke up gradually over the next half an hour, recovering slowly after hours of anesthesia. She wasn't awake for long, though, before the nurse noticed early signs of trouble in her neurological examination. Minutes later she was unresponsive. A head scan revealed a catastrophe: massive bleeding into the brain, including the delicate brain stem. The surgeon went through all the right motions of a heroic rush back to the operating room, but the damage had been done and he knew it. The bleed was fatal.

Despite all good intentions and a technically successful operation, the woman's brain could not tolerate the perturbations in circulation that accompanied removal of the large tangled mass of vessels. Maybe an otherwise normal artery in



In the OR (Firlik, left): "Infection is always a risk. If you are unlucky, should you blame your surgeon? Should you call your lawyer? I have never been sued, but I expect to be."

her brain, not accustomed to the new pressure dynamics, broke open. Or a critical vein near the malformation may have clotted off, leaving too few outflow options for the brain's rich blood supply. Whatever the explanation, I imagined that this was the AVM's final demand for respect, with her scan representing a "don't touch" warning to surgeons tempted to offer other patients like her more than just a handshake. It was also a tragic introduction to the mantra I would hear again and again through my training: "The patient is the one taking the risk, not the surgeon."

Years later, as a senior resident, I met another patient with a handshake AVM. She had resigned herself to inaction long ago. This woman's AVM was so large that it extended across the corpus callosum, one of the structures that connect the two hemispheres of the brain. Although she was otherwise a healthy and active woman in her 30s, she had lived her life with full knowledge of the tangled mass that would always be with her.

This woman had never suffered a devastating bleed. Instead there were a few defined episodes in which the malformation leaked small amounts of blood into the brain. (This scenario is typical for the largest of AVMs. The smaller ones are more likely to cause larger bleeds for various reasons.) Luckily, these small bleeds were in the relatively resilient frontal lobes, and the patient suffered bad headaches but no significant neurological conditions. When I met her, she was in the hospital for a few days after one of these bleeds,

and my job was to check on her and make sure her blood pressure and her headaches remained under good control. That's about all we had to offer, and, luckily, that's all she needed.

Had these two patients, victims of random developmental circumstance, been given the chance to meet each other, what advice would the elder have given to the younger? It is clear that the brain can accommodate quite nicely to the overbearing presence of a malformation, but can the mind be trained to accommodate just as well? When inaction is the best action, how do you prevent fear itself from becoming an illness? Does the fear simply wear out, or does it have to be forced out?

#### **Blunt Is Best**

Knowledge is power, but it can also foster fear. Surgeons are obligated to educate patients about their condition and treatment options, but then doctors are faced with managing the anxiety that goes hand in hand with that knowledge. I have found that handling a patient's anxiety can be more complicated, and sometimes even more time-consuming, than the surgery itself. Some

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As adviser: "Some surgeons prefer patients under anesthesia to patients wringing their hands over a decision. Others find those interactions rewarding. I tend toward the latter."

surgeons loathe this part of the job. It reminds them of all the reasons they didn't go into, say, psychiatry. They prefer patients under anesthesia to patients wringing their hands, crying and reading off a list of questions from everyone in their family. Others find those interactions rewarding. I tend more toward the latter camp, but I do empathize with those in the former.

Because anxiety management is not always enjoyable, some surgeons don't spend much time on it. I remember, as a resident, having to recalibrate a patient's thoughts. She was convinced that she was dying of a brain tumor. She had a small benign tumor, called an acoustic neuroma, on one of the nerves at the base of her brain. She had no symptoms. The tumor was discovered incidentally, when her head was scanned for other reasons. She was elderly, and a surgeon at another institution recommended doing nothing for it. She left his office thinking, "I have a brain tumor, and nothing can be done for me."

I saw her and her extended family a few months later, when a relative urged her to seek an opinion at our institution. She looked around at her loved ones in the room and expressed regret that this would probably be the last Christmas she would spend with them, as death was near.

I went over her MRI and examined her. I explained the reality of her small benign tumor at the base of her brain (not *in* her brain), and told her that it could have been there for quite a while. Most likely, she would die years down the line from a totally unrelated cause, before this little tumor could ever cause a significant problem. I went over all the options, and we settled on the one everyone

was most comfortable with for the time being: observation. I was happy to be of service, as it is always gratifying to extend someone's life expectancy without even having to pick up a scalpel.

During my training, I took to observing how different neurosurgeons interacted with their patients in discussing the risks of surgery. I knew I would have to devise my own personal style, but I figured I could pick up on what seemed to work and what didn't. On one extreme was the warm hand-holder who peppered religion-speak into his counseling about what could possibly go wrong. ("We'll get you through this, with God's grace.") That style did work wonders, especially with the older ladies, but I could never adopt it myself. The same surgeon was effective in conversation in other, more creative ways as well. I observed him discussing a difficult situation with a patient and her very large, extended Italian family. He was trying to get across the fact that the tumor at the base of her brain would be tricky to remove because of all the nerves draped across it. After thinking about it for a few seconds, he explained, "It's like trying to get at a large meatball when there are strings of angel-hair pasta in the way."

On the other extreme was the guy who, I'm a bit ashamed to admit, was entertaining to watch in a sadistic sort of way. There is only one word to describe his style: blunt. Here is how he would describe the risks of surgery for an aneurysm of the brain, just prior to having a patient sign her consent: "You could have a stroke. (Pause.) You could have permanent brain damage. (Pause.) You could become a vegetable. (Pause.) You could die." Although these statements were technically

correct, the monotone voice with which they were spoken, and the sharklike demeanor that went with them, exemplified his uncanny ability to make a patient and her family burst into tears.

Needless to say, I didn't adopt this style wholesale, either, but I did appreciate the warning this surgeon left me with: if the patient isn't crying by the time you're done going over the consent for surgery, then you haven't done your job. Although I don't force an upwelling of tears from each and every patient, I agree with the spir-

one's fault. There is no such thing as bad luck.

Based on the alarmist tone of her voice, I imagined that in *her* mind, the surgeon willfully smeared bacteria into the surgical site, leading to fever, pus and a red, swollen incision. The truth is that infection remains (and will always remain) a risk of any surgical procedure. Although all measures are taken to bring that probability as close to zero as possible, it still hovers around 1 percent (or slightly higher or lower, depending on the surgical site, the circumstances and how healthy the

### The brain can accommodate malformation, but can the mind? How does a patient overcome fear of inaction?

it of the advice: the risks of surgery have to be laid out plain, in the open, and cannot be taken lightly. And even though some patients prefer not to hear all the risks and just want to get the signing over with (worrying that if they hear too much, they'll change their mind), I think it's in their best interest to know everything anyway.

Furthermore, from a surgeon's point of view, the last thing you want is for a patient to come back after surgery saying she had no idea she could end up with: an infection, headaches, nerve damage, a numb foot, an ugly scar, a less than perfect outcome (take your pick). The next person the surgeon will hear from is a lawyer.

#### Sue Me Not

A patient's attitude, of course, complicates the discussion over risk. I saw a patient recently who had had spine surgery a few years earlier. As is often the case, the original reason for the surgery—advanced arthritis that can occur with age—continued to worsen. She was now faced with a second possible operation, for a neighboring part of her spine. I knew the surgeon who had performed the first operation, a highly reputable colleague, and I voiced some question as to why she wasn't in his office instead.

"Well, he gave me a wound infection, so you can be sure I won't be going back to him!" This sort of statement, and the vehement emotion that goes with it, raises a red flag. It might be easy for me to fall into the trap of flattery (the patient specifically chose me over the other surgeon), but the reality is that this is the type of patient who believes that the concepts of risk and complication are neatly and inextricably linked to another concept: blame. If something bad happens, it's some-

patient is). Surgeons feel terrible when a patient develops an infection, but they normally don't feel guilty. While it's true that in very rare cases, careless breaches in sterile technique are to blame, and certain individuals can be held liable, those are the very rare exceptions.

So if you are the unlucky individual who falls into that 1 percent because bacteria that naturally live on your skin (the usual source) infect your wound, should you blame your surgeon? Should you call your lawyer? Should you expect someone to pay up? One reason physicians are unhappy these days is that the definition of malpractice has changed. It is no longer defined as truly negligent or improper behavior. Now a poor outcome alone triggers claims of "malpractice." The quality of the care may be irrelevant.

I have never been sued, but I expect to be. The entire new generation of surgeons expects to be sued. Our elders tell us it's just a matter of time. It doesn't matter how good we are or how carefully we practice. For that reason, I'm always trying to figure out which of my patients might be most likely to sue me. If it's really obvious (they gloat about the lawsuit they won against Dr. Soand-So when surgery wasn't everything they had dreamed it would be), then I'm likely to steer clear of them and recommend definitive treatment elsewhere. Most of the time, though, it's not so obvious, and you have to go with your gut. Unfair? Maybe. Paranoid? Not at all. M

#### (Further Reading)

- Simple Risk Predictions for Arteriovenous Malformation Hemorrhage.
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- ♦ Brain and Neuro Surgery Information Center: www.brain-surgery.com