

Being Optimistic-the benefits of avoiding negative prognostication for both adults and neonates

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After a long career in pediatrics, neonatology and ultimately family practice, I have been reflecting on the many surprisingly positive outcomes I have witnessed among my patients, some of whom recovered intact and healthy in the face of almost certain death or extreme disability.

I once cared for a 615-gram premature infant who at the time was among the smallest known survivors at such a low weight. As I arrived at the birth, the mother delivered the tiny girl. The mother was a new immigrant, and within minutes she said in broken English: "Too small. No good. No want." She got off the delivery table and left the hospital.

Over the next six months, this baby had multiple respiratory illnesses, cardiac failure, diabetes, multiple infections and a series of metabolic catastrophes. We were unable to convince the mother to visit her baby.

By the end of six months, the baby looked beautiful but I was convinced that she was deaf.

Finally, at six months, the mother came to see her baby. Without hesitation, she said: "Nice baby. I keep." And despite what we think we know about maternal-infant bonding, the mother and baby never looked back. Mother had to learn English and sign language to be able to communicate with the audiologists and speech therapists.

If not for the baby's condition, the mother might never have left her Chinese-speaking enclave in Montreal and learned to speak English. The baby developed normally and did well in school. She graduated from McGill and planned to become a physiotherapist. This is a perfect example of the resilience of little babies when they're treated fully for their condition. This kind of resilience is not limited to sick newborns

My first experience with many patients who were not supposed to recover and did, was as a medical student at Stanford. I helped to care for a 10-month old with severe hemolytic anemia and a very large liver. At open operation his liver was full of a very aggressive primitive cancer. The mother was told that there was nothing to be done. Two years later his mother looked me up specifically to introduce me to an apparently normal three-year-old. Several fine needle biopsies showed no evidence of cancer. The mother's explanation: "I found Jesus and divorced my abusive husband."

Resilience in adults is illustrated in a powerful new book, *Fallen* by Kara Stanley.

In it, she details the care received by her husband Simon, who was in deep coma after falling off a roof in a construction site where he worked to support his life as a musician. On arrival to hospital by air ambulance, Kara was exposed to the first of many negative comments. The trauma doctor's initial dismal assessment, employing The Glasgow Coma Scale, was shared with Kara--3.3, the lowest possible score.

This scale is good for getting an idea of the prognosis of a population of patients, but it may not be useful for individual patients. I wondered why so many of us tend to emphasize the negative, rather than speaking of the incredible plasticity of the human brain and the amazing capacity, from very small newborns to adults, to recover and thrive after birth trauma or severe accident.

Post-craniotomy, which revealed Simon's severely damaged brain, Kara was given a relatively positive statement from one neurosurgeon:

"There is good tissue beneath the extensive trapped blood, which holds out some hope."

Soon after, a young neurosurgeon contradicted the senior neurosurgeon, saying:

"Simon's brain injuries are global and diffuse. If he survives, it is

impossible to predict which areas of the brain might be affected, possibly all of them. The bleeding in his brain is extensive, and blood is toxic to neurons.

Wherever there is blood, neurons have died. The underlying tissue does not look good. His brain is soaked with blood, like soup with neurons swimming in it."

Other comments from physicians:

- "His left pupil is blown."
- "Executive functions may well be lost." "Damage to the optic nerve is permanent." In days his vision was normal
- Early on, some doctors were talking about the possibility that Simon might wind up in a long-term facility.
- "Simon's brain will never be as good as it was before...The frontal lobes were so severely damaged that it is not clear that the brain will be able to heal, since the ability of the brain to heal is contingent on its ability to make connections."

But a rehabilitation nurse said:

"You spend days working with someone you are certain is hopeless. A few weeks later you meet them in the hospital hallways, awake and responsive. Then it all feels worthwhile"

Kara's positive outlook was also partially based on reading the story of neuroscientist Jill Bolte Taylor² who mysteriously recovered from a devastating stroke and also from reading the story of my wife, Bonnie's book: "Slow Dance," about her recovery from being quadriplegic and locked in.

While Simon is now paraplegic, he has recovered full use his upper body and his hands. He is fully engaged with his family and is a well-regarded musician who lives a positive and productive life.

My wife Bonnie had a severe brain stem stroke based on a large congenital vascular malformation, which occupied most of the medulla on one side and part of the pons and crossed the midline. She was considered inoperable at the famous Montreal Neurological Institute and was expected to die. Our family struggled against the negative prognosis. With help from a Stanford Medical School classmate who was a neurologist in a distant city, we found a London Ontario neurosurgeon who had been practicing on dogs and waiting for a patient. Patients with such a low brain stem bleed usually die from respiratory failure before they get to the neurosurgeon. This is because the malformation is so close to the respiratory center that the neurosurgeons have little experience with operating in this part of the brain.

On a respirator for many weeks, among other serious deficits she had a permanently paralyzed vocal cord. A speech therapist told her she would never talk. She talks normally with only one vocal cord, takes a few steps, drives a scooter, is a writer/filmmaker as she was before and is completely independent.³⁻⁵ What about patients without advocacy?

Neonatologist Saroj Saigal has followed very small infants in the range of 800-1000 grams at birth, for an astonishing 30 years, beginning in the era when neonatology was just developing. She compared them to a

matched sample of babies of normal birth weight at the same institution and time.^{6,7}

Most of the tiny survivors live normal and productive lives, are married and have educational degrees. While some have minimal deficits and a few have severe deficits, overall their quality of life and function as a group is comparable to the normal weight newborns.

How shall we talk to family members in the face of life threatening illness? What are the consequences of negative prognostication? Are we afraid to be wrong, or to give 'false hope?' Is this key issue part of the undergraduate and postgraduate medical school curriculum?

A better approach to family members of very sick and apparently damaged newborns or adults is to be modest, saying: "While I am concerned as you are, I have seen patients just as sick who recover and some who ought to and don't. I can't know in which category your family member will be. I do know that negative prognostication can lead to the family giving up and withdrawing, while families who engage with their sick family member enhance recovery. "

If you give a definitively negative prognosis, families will never forget. If you give a relatively positive or "wait and see" prognosis and things do not go well, you can always change your mind.

References:

1. Stanley K. *Fallen: a trauma, a marriage, and the transformative power of music.*: Greystone Books Vancouver/Berkley; 2015.
2. Taylor JB. *A stroke of insight.* Penguin Group USA. 2008.
3. Klein MC. Too close for comfort: a family physician questions whether medical professionals should be excluded from their loved ones' care. *Canadian Medical Association Journal* 1997;156:53-5.
4. Klein BS. *Slow Dance: a story of stroke, love and disability.* Knopf Canada;1997
5. Klein BS. *Film: Shameless: the art of disability.* National Film Board of Canada.2006
6. Saigal S. Quality of life of former premature infants during adolescence and beyond. *Early Human Development* 2013;89:209-13. doi <https://doi.org/10.1016/j.earlhumdev.2013.01.012>
7. Saigal S. Functional outcomes of very premature infants into adulthood. *Seminars In Fetal & Neonatal Medicine* 2014;19:125-30. doi <https://doi.org/10.1016/j.siny.2013.11.001>

Author note: Similar issues and many others of interest to family docs are explored in greater detail in a forthcoming book. Michael C. Klein. *Dissident Doctor-My Life Catching Babies and Challenging the Medical Status Quo.* Douglas & McIntyre. August 2018.