



Editorial: Follow Your Brain, Not Your Heart

By Lester Y. Leung, MD, MSc
Director of the Stroke and Young Adults (SAYA) Program at Tufts
Director of the Comprehensive Stroke Center at Tufts Medical Center

Far from your homes and your doctor's office, a quiet war is being fought over a definition. In a distant conference room and behind closed doors, a group of World Health Organization policy makers are creating and revising an encyclopedia of disease classifications: the ICD-11 (doctors and hospitals currently use ICD-10 for behind-the-scenes billing and resource allocation). The conflict is over a deceptively simple question: is stroke a circulatory disease or a disease of the brain?

Why should this matter to you? For many of you, this distinction will not make a difference: you had a stroke, your neurologist helped you uncover the cause, you are recovering and adapting to any residual neurologic deficits (disabilities), and you are now better protected from your cause of stroke than you were before with a real and well-founded hope of never having another one. Whether you were aware of it or not, you traveled down an organized, logical, and systematic pathway that coordinated the efforts of your doctors, nurses, and therapists.

On the other hand, some stroke survivors may never see a neurologist, have their cause of stroke discovered, or have their uncertainties addressed: this sometimes results from a lack of available neurologists (particularly in rural areas), but this could also result from no one telling a stroke survivor that he or she should see a specialist of the brain. This is particularly concerning for young adults with stroke: stroke is often misdiagnosed or not recognized in young adults, both by the people having strokes as well as by medical providers. In some cases, when a stroke is finally diagnosed after some delay or confusion, the stroke survivor may be sent to a cardiologist (heart specialist) or a vascular surgeon (blood vessel surgeon) without first seeing a neurologist to guide the investigation and treatment of the true underlying cause of the stroke and address the impact of the stroke on his or her life. In such cases, stroke survivors may undergo unnecessary procedures or surgeries that fail to prevent stroke from that individual's true cause. In other cases, without the guidance of a neurologist, the young stroke survivor is left wondering: what now? Where do I go from here? What is my body doing, and will I get better?

The human body is complex and cannot be too rigidly compartmentalized: no part of the body works in isolation. The nervous system reaches and controls all parts of the body, so neurologists must always have a holistic, “whole person” perspective. Blood vessels that carry oxygen and nutrients are directly involved in almost all mechanisms of stroke, but blood vessels supply all parts of the body. Traditionally, blood vessel diseases have been grouped with the heart (“cardiovascular”), but it’s clear to all neurologists and many other medical professionals that not all stroke is connected to the heart. For example, young stroke survivors who had a subarachnoid hemorrhage or an ischemic stroke due to an arterial dissection will not gain meaningful insight or guidance from a cardiologist. What then, is the common denominator for all strokes?

Stroke is a disease of the brain and the central nervous system. It can happen to anyone, at any time, of any sex, at any age. It is also incredibly varied in how it might affect you: while a heart attack may cause a half dozen symptoms at most, strokes can cause a hundred or more different symptoms. Most doctors and nurses without neurology training or stroke specialization are only familiar with a small fraction of those symptoms and may have limited or no insight into the challenges faced by stroke survivors. These challenges—persistent neurologic disability, late complications, and tears in the social, psychological, and financial foundations of our lives—are more prominent in young adults with stroke and stretched over decades of life.

So, what’s in a word? Think about how you use a dictionary or encyclopedia to gain knowledge: how do you know how to find something without knowing the first letter? In health care, the ICD disease classification is like that first letter: it sets up a framework for how health care is delivered and how resources are allocated. It places labels on medical conditions that have downstream effects on how doctors, nurses, insurers, and policy makers address the needs of patients. In the case of stroke, this disease has been in the wrong part of the dictionary (“circulatory diseases”), leaving patients confused, disempowered, and uncertain where to turn for help and guidance.

The WHO appears to be swaying back and forth in its decision to classify stroke and other blood vessel-related diseases of the central nervous system (“cerebrovascular”). For neurologists and knowledge-empowered stroke survivors, the answer is clear. For those without the knowledge that stroke is a disease of the brain, it’s up to us to help them find the right path to answers.