Certain Uncertainty
Life After Stroke From the Patient’s Perspective

Deidre Hannah, MSN, RN; Brianna Lindholm, BA; Lesley Maisch, BA

A 38-year-old with a Masters in Nursing, a 30-year-old business development manager, and a 59-year-old administrative assistant; each of us comes from a different walk of life; yet, we all have one thing in common: we are stroke survivors. We are also actively engaged with support groups and stroke researchers and have become energized to share our collective viewpoint with the medical community. On each of our individual paths to recovery, we have learned that the only thing certain is uncertainty. Medications that are supposed to help sometimes do not. Patients with seemingly similar prognoses recover in different ways, at different paces. We encourage physicians to join us in accepting that the future is unpredictable and to work alongside us, as we navigate our recovery together. Three specific areas where healthcare providers can best support us are the following: (1) managing the balance of hope and expectations; (2) acknowledging that a stroke changes not just what we can do, but who we are; and (3) making the most of communication opportunities with us (the patients) and our caregivers.

Loss of Independence and Role Changes
Among the greatest challenges, each of us faced during stroke recovery was the loss of our independence, and the consequent dramatic shift from being the caregivers to being the recipients of care. Before our strokes, each of us was a driven self-reliant career woman, who could confidently give presentations to hundreds of people, run 5 miles several times a week and lead a busy social life. Yet overnight, we were forced to be dependent on others. Even the most basic activities—reading, dressing, and walking—sometimes require assistance not to mention intense personal concentration. Things that we never gave much thought to before, like the weather or the condition of a parking lot, determine whether we run errands or meet a friend for a meal. Following our strokes, each of us spent some time being angry, bitter, resentful, and frustrated by the ways in which our lives had changed. One of us was the mother of a 2-year-old at the time of her stroke, and she felt deprived of being a mom because she was literally just trying to get through each day. Healthcare providers often measure our recovery with functional status assessments and activity scales, but what these metrics cannot quantify is the tremendous loss felt by the driven career women, the supermom and superwife, or the free-willed adults that we all used to be. Our strokes have not only changed how we live, but who we are. As we grieve these losses, healthcare providers need to support us by acknowledging that the future is uncertain and empowering us to shift our focus from what we cannot do, to what we can do.

Hope and Expectations
One of the most essential, yet often most difficult, aspects of communicating with stroke survivors is remaining cognizant of the delicate balance between hope and realistic expectations. As patients, we understand that the worst case scenario is possible, and a healthcare provider feels obligated to tell us of this possibility; however, predictions of stroke recovery (or lack thereof) are too often presented by healthcare providers as absolute certainties. Each of us has been told at least once by a medical professional that we would never walk, talk, or eat again. Had we taken those predictions to heart, we would have been too discouraged to devote any serious effort to rehabilitation, and we may not have been able to do any of these things today. Conversely, overly optimistic projections leave us frustrated and disappointed if progress is slower than anticipated. One of us was told by her physician on her first rehabilitation visit that she would be walking normally 5 months after her stroke, but 5 years later, she still uses a cane. Although some neurologists have indicated that she looks fine or is doing much better than a lot of stroke patients, she is still not able to do things the way she used to be able to before her stroke. These seemingly positive passing comments on the part of healthcare professionals invalidate the losses we experience from the life-changing effects of a stroke. Every patient is unique with regard to their speed of recovery, personal goals, and expectations. Acknowledging these differences and becoming comfortable with the uncertainty surrounding an individual’s recovery are the most honest and compassionate way a healthcare professional can support us during this process. The cycle between hope and discouragement are commonplace and a normal part of a stroke survivor’s world.

Opportunities in Communication
The efficiency that is so highly prized in today’s medical practice often presents a major burden to stroke patients. For
example, asking multiple questions by several providers in a single examination room is extremely stressful for a patient whose mind has been suddenly altered. Simple changes to the status quo would greatly improve our ability to understand and follow your recommendations. First, slow down when you speak to us. Second, use visual communication, which is an increasingly rare tool in the practice of medicine. Show us the results of our x-rays, CT scans, and MRIs to help us see what you see. For most patients, no amount of written reporting (particularly when filled with medical terminology) will result in the same level of understanding as a targeted visual. Third, make eye contact. In the world of electronic health records, face-to-face interaction has been greatly diminished, yet few things are as vital to establish an open, honest, and trusting physician-patient relationship. Fourth, be transparent about your communication with our other providers. There often seems to be little interaction between members of our care team other than office visit notes and test reports that are passed back and forth between one another. As patients, it is unclear whether a report has been read, much less discussed, among all of our providers. The patient is tasked with maintaining and relaying all the information from the primary care physician, cardiologist, neurologist, medical rehabilitation doctor, physical therapist, occupational therapist, ENT specialist, and gastroenterologist, which seems inappropriate given our condition, not to mention that we are not sure we understand everything we have been told. We need reassurance that each member of our care team is informed and invested in our recovery. Finally, it would be helpful to fully understand the potential side effects of medications and procedures. Given that we are already overwhelmed, understanding the possibilities would better prepare us for our new change of life.

The Patient Role in Research

As patients, we appreciate that the astounding pace of scientific discovery often brings with it fresh uncertainty: as new findings are published, new questions always arise. One of us found out through genetic testing that one of her sons has inherited the same blood clotting disorder that caused her own stroke, but what can she do to help reduce his stroke risk? Clinical trials have led to the development of new blood thinners, but can these reduce the need for monitoring and actually improve quality of life? The complexity of these issues requires creative thinking, multiple perspectives, and perhaps most importantly, input from patients that are personally affected by the successes and pitfalls of modern medicine. As patients, we must accept the responsibility of being advocates for our own healthcare, and we cannot do so if we are not empowered by a fundamental understanding of medical research. To date, healthcare research and the general public have largely existed in separate domains. Yet, recent efforts to integrate patients into research teams hold significant promise for narrowing this gap and encouraging a much-needed paradigm shift. All 3 of us are patient coinvestigators for the Patient-Centered Research Into Outcomes Stroke Patients Prefer and Effectiveness Research (PROSPER) study, which is a Patient-Centered Outcomes Research Institute (PCORI) initiative that is examining stroke outcomes, as prioritized by stroke patients. As coinvestigators for PROSPER, we are working alongside doctors and scientists to answer key questions about quality of life, depression, and fatigue that have often been neglected in clinical trials. Although some answers may elude our collective efforts, we are certain that we are progressing toward a new type of medical research that is centered on patient values and needs.

The Path Forward

A personal anecdote offers hope that doctors and stroke survivors are acknowledging that, by accepting uncertainty, we can begin our difficult work on the path to recovery. One of us recalls, "When I was admitted to the stroke hospital, the most helpful information I was given was by the neurologist on call. My symptoms worsened the day after admission; I was scared to death and felt like nobody would talk to me. More than anything, I wanted to know when I was going to get better, so I asked the neurologist how long it would be before I was back to my normal self. He leaned in close and whispered, 'It could take weeks, months, or years.' His answer was not definitive, yet that statement gave me something to hold on to, something realistic; it eased my anxiety in the frightening environment of the unknown. And that was good enough for me.'"

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