PSYCHOLOGICAL IMPACT OF STROKE: A RECOVERING NURSE’S STORY

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The author, both a nurse and patient, suffered a massive stroke. Included are the internal and external struggles and how to cope. Derived are lessons learned for nurses, to more fully understand a person with a stroke.

There are many books and articles about stroke. What then do I have to offer that is different? I possess the idea that I would not only get better from the stroke, but “completely” better despite what anybody said. Actually they said a great deal, very negative as far as I was concerned. To be fair, I guess they advocated the conservative approach. I understand that with my type of stroke there was about an 80% death rate. Those who lived had severe one-sided (arm and leg) paralysis, and varying speech and cognition problems.

I was not expected to work or, if I did, I was to select something part time at a much diminished level from my former employment. The bottom line is that if I’d listened to the professionals, I would not have tried so hard and I would not have the life that I do today. The will, at least in my case, makes a huge difference.

GETTING THE IDEA OF STROKE

My first recollection after the stroke was waking up in the intensive care unit after being in a coma for three days. It seemed to me that I was just asleep, but that was not what anyone else believed. I did not comprehend that I really had had a stroke. I had no precursors. I was thin, drank very little, never smoked and had low blood pressure. I was

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in good health, active, and had no family history. Even today, they still do not know why it occurred.

I knew I was 52 and only my maiden name, not my married name. My son, who was 23 at the time, seemed to be the same age as my husband. You would think that I would be glad to see my family but, in fact, I did not recognize them.

Most of you do not know me. I have worked almost 27 years in nursing, possess a doctorate, and have contributed to patient care by writing and publishing. I tell you this so that you will realize I’m in somewhat of a unique situation in that I have experienced both sides of healthcare: that is, a nurse’s position, but also as a patient.

In the beginning I was mentally struggling just to write a complete simple sentence. I vaguely recalled that I lived somewhere in the north. My thinking and consequently my ability to write was severely affected. In about six days I started to remember some people’s names and in another three months began comprehending what had happened.

Because of aphasia, communicating my wants and needs, even about trivial things, was very difficult. For example, when filling out my food choices, I couldn’t completely identify a corn muffin. I could only check corn muffin on the menu. Another example, I had ordered diet yogurt; instead they brought regular yogurt. I could not explain why I wanted diet yogurt. The dietitian told me I was too thin, patted my arm and said I would eat regular yogurt. Well, I just didn’t eat yogurt at all until somebody finally had the idea that I only wanted the low fat variety. It sounds trivial, but I had so little control of my life that “little things” became very important to me.

I could not formulate, even internally, a quick enough response, and then express myself. I would cry in utter frustration. I just wanted, what I wanted, and that was it. My mental change was profound.

People think my determination came from a positive attitude. Nothing could be further from the truth. I was extremely depressed and angry, not at any one person but in general. I was not particularly difficult, in my opinion; but, “I was going to get much better.”

The first day at the rehabilitation hospital was terrible. I climbed over the bed safety rails and fell to the floor. Twice. I was a serious risk because I was on blood thinner. The hospital staff thought I had poor impulse control since this is common for some stroke patients. I don’t know if this was the case for me or not, but they never understood when I had to go to the bathroom. They pointed to a call button, which I didn’t recognize at first. When I tried to use it, it didn’t work and I could not explain to them that it was defective. I was hospitalized for two months and then was an outpatient in a day treatment program for an additional four months.
Stroke victims often cannot speak for themselves and yet they must make decisions that affect their entire future such as the type of treatment required (Sife, 1998). It is extremely helpful to have a patient care advocate. My advocate was my husband of thirty plus years. He was the only person who was convinced that I would improve greatly and resume my life: ride a horse, water-ski, and type with two hands, particularly necessary with computer work. I did not believe him, however. I repeated the future outcome predicted by my doctors. My husband’s positive attitude of expectation did not change. He would attend my conferences and was very active in my dispute with managed care. The cost to managed care was based on my doctor’s poor prognosis.

**PSYCHOLOGICAL IMPACT**

Stroke tyrannically redefines everything. When confronted by its terrible ultimatum, it would cause either the downfall or the rebirth of the survivor (Pohjasvaara, Vataya, Leppavuori, Kaste, & Erbinjuntti, 2001; Visser-Keizer, Meyboom-de Jong, Deelman, Berg, & Gerritsen, 2002; Zgaljardic & Borod, 2002). It forces a person to either accept responsibility for their existence in a newly flawed body or sink into despair and utter personal destruction. The stroke suddenly happened and nothing was the same. I accepted responsibility for myself but in the “temporarily” flawed body. We have made the choice of being the victim or survivor and we must claw our way through a “horrific odyssey” in an existential struggle for personal definition (Sife, 1998). The horror of a stroke cannot be imagined. I thought I knew what tough times were before my stroke but I was only acquainted with the tip of the iceberg. I do not think that a person who is not a stroke survivor has any idea of the magnitude of the loss. One of the wishes of stroke survivors is to tell others of their hellish experiences and to be able to be reborn out of the horrors of a stroke (Sife, 1998). It is for this reason that I share my story.

If stroke only caused paralysis and a danger of death, it would be a terrible affliction, yet the biggest tragedy of stroke lies in its mental effects. Most of the disability it produces is mental rather than physical (Birkett, 1988; Bodini, 2004; Eslinger, 2002; Stone, Townend, Kwan, Haga, Dennis & Sharp, 2004). It can be tempting to hide one’s pain and overwhelming disability, but in the long run we can’t really hide from ourselves (Vance, 1998).

**PHYSICAL LIMITATIONS AFFECT WELL-BEING**

My physical and occupational therapy involved long hours of gaining function of my leg and arm. I attempted to learn to stand and
then to take a step or two. A four pronged cane and brace aided my effort.

There comes a time when every patient reaches a final plateau in recovery, and is told by their doctors and therapists that his or her physical dysfunctions will not improve further. This is so personal and staggering a blow that even many professionals can not comprehend its impact. It is a profound and traumatic experience. All at once, the patient feels abandoned; left without help or hope. The professionals seem to have given up on the patient, and the psychological impact is overwhelming. At this point the patient is officially pronounced a prisoner for life in a dysfunctioning body (Sife, 1998, Vissor-Keizer et al., 2002). Despite my effort, I had not made a great deal of progress. The staff informed me that I would probably progress up to nine months, maybe a year. After that, I should be about “where I was going to get.” This is a bleak sentence and is a depressing outcome of even the best of therapy programs.

When therapy is ended, the recovering patient can hit bottom, emotionally. The depression is terrible, and suicidal thoughts are not uncommon (Pohjasvaara et al., 2001). The stroke patient has become a physical misfit in an impatient and confounded society. The patient feels inferior and defensive, and wants only to remove him or herself and hide. There is a terrible sense of worthlessness and guilt in imposing oneself on others. Despairingly, the patient finally accepts all the negative labels and responses they have fought and rejected before (Sife, 1998; Visser-Keizer et al., 2002; Zgaljardic & Borod, 2002). Who among us has never experienced moments of the “worthless me” syndrome? By feeling inferior, the stroke victim may impede or even reverse the continuation of his or her own healing process. Intuitively, though, he or she may begin to realize that there is still much more to healing (Sife, 1998; Visser-Keizer et al., 2002).

The healing process must go through torturous but predictable changes. The intense sense of personal loss parallels the psychological reactions one has when greeting the death of a loved one. Indeed, there is bereavement, in a sense, the old self has died. The loss is intense, traumatic, and permanent. But this, too, will pass, if one’s potential courage and individual spiritual strength are mustered doing it (Sife, 1998).

**OBSESSION WITH MINUTE DETAILS**

I became obsessed with minute details and this allowed me to see progress. One of my outstanding achievements was tying my shoes myself. It sounds so trite but is overwhelming. It was a major turning point when I could actually tie my shoes, although to accomplish it took about
a half-hour. I remember crying uncontrollably. I never thought I would be able to tie my shoes again by myself. I thought I would just have to get used to the fact that I was different. And then, I wasn’t so different after all. As I read this over, it sounds as though I progressed rapidly, but in fact, it was laborious. Day after day of even being able to touch the shoelace, another eight months of teaching my hand to move enough to even hold onto the lace, and so forth but I could see progress. The progress was minute, yet the accumulation would result in a leap forward that would come after slaving for days.

I do not know what made me keep going. People often ask me about the choice. Actually, I felt, and still feel, there is no choice. Many people say I’m an inspiration to them. To me it is quite different. I simply did not want to live in my current state.

As I started to do better with my life-long physical activity, I began to feel more positive. I even had fantasies of being a hero. As I think about it, it was because I was doing something that I felt so much better. Being inactive is most difficult. I start to feel helpless. It is probably this quality that has made me so successful, but not necessarily happy, as I have dealt with my stroke.

Bike riding was one of the most difficult endeavors, particularly keeping my balance. The worry of my maintenance on a blood thinner is never far away, therefore I do a lot of preplanning to minimize any difficulties. I tried riding in a parking lot on Sunday morning when there would be little traffic. My husband and my son set me on the bike and stayed within an arm’s length on either side. I was terrified but I didn’t fall. I couldn’t turn well in one direction and made wide lopsided circles. I needed to learn to get on the bike myself. Finally I learned to place my affected foot on the pedal at its highest position, tip the bike toward my “good” side and swing my leg up. I was frightened but successful. I was triumphant.

MY MENTAL CHANGE

My personality went through changes, too. Sometimes I would be afraid of appearing “crazy.” Letters from Stroke Connection confirm this feeling, for example, in addition to the physical loss “the stroke has also damaged and shattered my mind.” Another person writes “My reality is a lonely dark, empty place. I too often ask is this what losing your mind feels like?” (Letters to the Editor, 2005).

At work, I could not tell people who I was on the phone. I would simply say hello. I needed to make a proper introduction but I just did not feel like I was the person they had called.
I sometimes felt strange and detached from reality, like I was watching myself from an outside vantagepoint. It was so stressful I’d break down and cry. Much later it was hypothesized that I suffered from a posttraumatic stress reaction to my stroke.

Looking back I realize that when I trusted people, I monopolized their time. I became so absorbed with my stroke. That’s all I talked about (Vance, 1998). My friend was tired of hearing me talk about my stroke. She missed the conversations we once enjoyed. Repeated conversation about the stroke was my way of coming to terms with what had happened. It was a stage that I had to navigate. I also acted impulsively and said whatever occurred to me—good or bad. For example, I would tell total strangers that “they didn’t work hard enough” or were “too fat.” I knew it was rude, but I didn’t care.

I became much more fearful. A year after my stroke, while on a cruise, I became hysterical during a practice lifeboat drill. I now depended greatly on my husband and the vulnerability was catastrophic.—Anything to not be helpless.

Handling all these personality changes has been complicated. At first, I saw a psychologist, but my speech was so limited that there was minimal value to our visits.

Reading words was a problem, too. I could see a word or sentence in lay publications but not make any connection to me with the larger world. In essence I could not read because it was hard, too hard, yet, incongruous. While watching television or reading a magazine was too difficult, I could concentrate on my research.

I wondered if my unconscious might not be affected by the stroke. Sometimes I will remember details from long ago, things that I had never thought of before my stroke. Now I dream of relatives that I have not seen in 40 years and, in the dream, easily remember their address and phone number.

My unconscious allowed me to solve a perplexing problem, for example, to figure out how to get a recording tape ejected. It seemed stuck. I thought there was a button to push but did not know which one. It took several tries to figure out. Finally, I pretended I was taking out the tape. The motion was correct and I found the button.

I unconsciously became repetitive. For instance, I used to park my car in the same place every morning and there were perhaps ten parking places from which to choose. One morning it snowed and the only place that wasn’t cleared of snow was my parking place. My husband asked me why I struggled to park there. Other parking places were in fact much easier to negotiate. I had to stop and think. It was just routine. In retrospect, there is nothing sacred about my parking place. I could
have gone to the parking place next to it and it would have been fine, but I was missing an awareness that I could stop and think that I have a choice of where I park. In later thinking about the situation, I realized that I did many things by rote. It became obvious to me that I could judge where to park by any number of things including the amount of snow left in the parking place. This sounds so banal, but after a stroke it happens.

When anxious, I do not speak as well as I do at other times. I also try to hear what I say instead of just saying it. For instance, I’d stumble over words as I try to listen to what I was communicating to someone. If I stop, I lose my thought. I was doing too many things at once. I have learned “one at a time” but it is extremely hard. I finally just tell people that I may make a mistake or just can not find a word. Most times I will realize it, but sometimes I will not. The worst is to pretend that a possible error did not occur. When I relax a bit things go better.

I had difficulty remembering details of my work. A particular stimulus will “open the door.” I did not even know how to turn on my computer. I have never been a computer genius, but everything I knew seemed eradicated. My secretary labored to teach me how to turn it on, and so forth. Suddenly, once it was turned on I remembered the details. It seems as though much of my work is like that. I read the first couple of lines of a manuscript, and then everything comes back, including the reference list. It is my recall of perhaps unconscious material becoming conscious again, or providing a small stimulus and getting a gargantuan response.

A NEW STAGE-ADJUSTMENT

I can begin to allow the positive and negative feelings rather than this one-sided obsession with detail. I have much less of a problem with walking or moving my hand now, and people may not realize I have had a stroke. I used to think that there would be nothing better. But “normality” brings problems too. Now I have to explain what’s going on with my speech if I have an “aphasic” attack. What I mean is that I will be speaking fluently, become a little excited and I will forget everything. Before, people just assumed it was stroke-related. If however, I always refer to the fact that I’ve had a stroke, it does not push me to the next step and that’s where I want to be.

I used to have times when I would feel sorry for myself. However when I went to a group for aphasic people as a guest speaker, and it was amazing and disheartening to see these people (my people) try to speak. To be positive, I could help them. For example I gave them much more
space to talk rather than rushing in to say something. In a way, I feel that I almost bridge between the two worlds, that of the stroke survivor and the rest of society.

I often feel so bad about myself at work, as though I’m never on top of things. I don’t feel good for very long. I think of my performance ratings as a teacher compared to those the participants gave me. I felt much more “out of it” than perhaps I was. The participants gave me all outstanding ratings and I thought I just did fair and sometimes not even that good. I became aware that I felt I had to start “at the beginning” or “at the bottom” since I did not know what to expect of myself. I think I have to prove myself to myself all over again. Can I imagine doing something well and being okay?

Decision-making is important. It seemed to happen automatically before the stroke, but after I remember being told to complete a written exercise. I explained to the instructor that I had already done the exercise. Before the stroke, I would work things out in my head and would tell my boss “it was all finished.” Both she and I knew that I meant I had solved the dilemma and that it was yet to be put on paper, but that I would do so. After the stroke, however, it was more problematic. I actually believed I was finished with a task because I thought it out in my head. I believed I had completed the task and the instructor thought I hadn’t done anything at all.

As part of this, I had to learn that there was such a thing as “moderation.” It’s another example of learning what I know logically but do not apply to myself. I can make steps towards something and it doesn’t have to be all or none. It’s this having to be perfect again. I had to learn to be “reasonable”—that I could have a few cookies, and not eat the whole box. Being “reasonable” also felt like being adult, more than like a child who wants all or none.

I have become more human as I grow. There is a balance between self-improvement and acceptance. For me, self-improvement means you strive to the nth degree. Acceptance is that you can see how things are temporarily, but only temporarily. My degree of denial is very high, and in this case, quite useful. Denial has allowed me to achieve what few have imagined.

My personality is evolving, from before the stroke. I can’t decide if the stroke is a huge obstacle that I must surmount and start all over again or if it is just a “hiatus.” The other way to look at stroke is that it is a major setback but certain things move along whether I had a stroke or not. Only now do I think that there may be some compromises I’ll have to negotiate. As I write this, it is too painful, so maybe I will put it away.
LESSONS LEARNED FOR NURSES

As I reflect on my own situation, there are points that apply to many people who have suffered a stroke. I offer them to be considered.

1. Truly listen to patients. Give them time to express themselves.
2. Do not be negative. A patient can progress far beyond a year if they are encouraged to do so.
3. Be cognizant of the need for understanding the progress of a patient’s written and verbal language. Listen for the meaning as well as recognition of words.
4. Recognize the need for attachment. It is much better to have a few consistent staff for the person’s care. A variety of caregivers is beneficial at a much later date.
5. Understand the importance of repetition, however, point this out to the patient in the future.
6. Offer the services of a CNS or other mental health professional. The patient can benefit from a long-term therapeutic relationship.
7. Understand during the first few years a stroke survivor constantly has to prove him or herself to him or herself.
8. Comprehend that with time, there is a movement from all or none thinking to making finer discriminations. The patient will then be able to include either both sides of an issue and/or arrive somewhere in the middle.
9. Teach the stroke survivor how to assert herself. She may have known before, but that isn’t necessarily true now. (Although I was in charge of a national grant, I had great difficulty moving into a leadership position. I had a flashback of when I couldn’t even make a follow-up appointment.
10. Assist the person to develop ideas of what they want to do—to set goals.
11. Encourage a person to attend a support group for survivors of stroke.
12. Allow the patient the time to identify as a stroke victim and then move away from that role to stroke survivor. Assist them to figure out who they are.
13. As time and their rehabilitation progresses, patients may consider how to assist others with stroke.

REFERENCES


