

Some Lessons I Have Learned From 25 Years in Clinical Neuropsychology: A Letter to My Grandchildren¹

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The practice and study of clinical neuropsychology is considered an empirical enterprise. However, such an approach may result in missing the more humanistic or phenomenological side of the experience of brain dysfunction. This addresses a personal journey rather than a professional and scientific one. In doing so, the limits of the discipline and the suffering and value of the experience of the illness are presented.

KEY WORDS: clinical Neuropsychology; neurological disorders; experience of an illness.

With the honor and privilege allotted to the role of President of the American Psychological Association's (APA) second largest division comes the unique opportunity of writing a Presidential Address. How could I write something of value that would stand the test of time? What would the topic be, I kept on asking myself. My career in this first specialty of psychology parallels the short but robust development of Clinical Neuropsychology. Should the topic focus on my research on cultural neuropsychology, my historical work on Roger W. Sperry, my organizational activities including the APA as well as the American Medical Association (AMA), the influence and observations of colleagues both here and abroad, or would it be a reflection on prior reflections. I went back and forth weighing the strengths and limits of each of these issues.

Then I began weighing the "how" I was to develop this address. Should it be a scholarly presentation, how about a review of the existing literature? After much thought, I decided to write a letter, a "To Whom It May Concern" letter. I wanted, after all, something personal

and something that at least some colleagues would find of value.

This letter was started soon after I was elected—approximately 2 years ago. If I was going to proceed with a scholarly presentation, it seemed judicious to summarize my work on the effects of culture on brain functioning, although some of my other research work is also of interest (e.g., neuropsychological effects of bypass surgery). Maybe I would talk about my problems in attempting to test Hispanic patients in the 1980s. There were no suitable instruments in Spanish at that time and it seemed appropriate and simple to remedy this situation. I would translate tests of interest and then use North American norms. First trying in Argentina (on a Fulbright), then in Puerto Rico (with support of APA's Visiting Psychologist Program), later in Spain and eventually in Russia and Brazil (with varied institutional support), I began a program of investigation to "remedy" this situation. In addition, I spent almost 10 years working with The Psychological Corporation on developing a Spanish version of the Wechsler (with the project succumbing during the late 1990s, I believe, to budget cuts—although I will never know for sure.). It might be of value to discuss how pursuing cultural research in Neuropsychology was not considered of much value in the 1980s (maybe not even now). And it would be interesting to outline how research of this type is much more complicated than imaginable. The interface of psychometrics, psychopathology, neuroscience, anthropology, politics, legal and financial aspects make for this type of research *to be* next to impossible

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to accomplish. For example, there is more to a translation than simply translating. Literal equivalence does not equal cognitive nor emotional fidelity. The same applies to norms. If it did, we are assuming that the effects of culture on brain development are negligible, imperceptible, immeasurable, and, therefore, not important. How egocentric and naive can a specialty be. In the search for a neuropsychological “g” I have been embarrassed, humbled, silenced. The search is more complicated and more exciting than I could have ever imagined. Despite it all, I persist in that search—and, maybe, it’s the search that truly counts in the pursuit of knowledge. A chronicle of this search and research might reveal the importance of being uncomfortable with the intellectual status quo and the excitement of alternative explanations. In some ways, however, this search, as important as it may seem to me, still leaves me with a yearning to share something more personal. So, after further thought, I decided to consider other topics.

Alternatively, maybe I should talk about the work of Roger W. Sperry, whom I have come to consider my intellectual mentor. Whereas most neuropsychologists appreciate the dichotomy of left versus right, verbal versus visual, there is much more to Sperry and his research than is commonly assumed. For example, the right hemisphere does have the capacity to communicate, may have a longer phylogenetic history and may be of greater importance in the control of human behavior than previously considered. Another critical, yet not commonly known point, is that Sperry’s split brain is one of several phases of his 50 year research program and that the split brain research was started by Sperry with cats and monkeys. Sperry began with motor function studies at Oberlin (MS with Raymond Stetson), continuing with research on nerve regeneration at Chicago (PhD with Paul Weiss), going on with studies on equipotentiality at Yerkes (postdoctoral fellowship with Karl Lashley), and the beginning of split brain investigations at Chicago and subsequently at California Institute of Technology. His elegantly simple and intellectually intriguing ideas resulted in his being the first individual trained at the graduate level in psychology to have received a Nobel Prize (Medicine and Physiology, 1981). However, less is known about Sperry’s work on consciousness and values. To him, research without direction and value is non-contextual and holds little societal usefulness. The application of his empirical findings to the study of the human mind and societal problems could serve as a wonderful foundation for a Presidential address of this sort. Further, the basic questions behind every research project were; was it important? Will it make a difference? However, as with my research on cultural neuropsychology, Sperry’s own work still left room in my quest for material

for an adequate Presidential address. After all, this address is about my ideas and not about Sperry’s.

Maybe I should talk about my professional activities as they are varied and, in many ways interesting in providing glimpses about the politics of science and profession. For example, I have served on the Executive Committee of Division 40 in numerous capacities, first being invited by former President Manfred Meier to serve as ethnic-minority representative in the mid-1980s at a time that my field was neither sensitive to the topic nor to people of color (they are getting there, very slowly). Maybe I should consider how it has been difficult to be President of a division that by design is an interest group, subservient to a larger organization, APA, and sometimes controlled by individuals whose interests and personalities are more self-serving than discipline and society-focused—all under the rubric of the pursuit of excellence. Alternatively, I could talk about how I become involved, first as Program Chair (in those days we used to print and mail everything ourselves) and later as an elected officer in the National Academy of Neuropsychology (NAN). NAN was a “re-negade” organization that most main stream clinical neuropsychologists considered to be for outcasts and second class citizens of our emerging specialty. Oh, how times have changed. Maybe I would talk about how as President of the North Carolina Psychological Association in 1989 I had the very adolescent idea of encouraging Blue Cross Blue Shield of North Carolina to develop a professional code for neuropsychological services that would allow for reimbursement. This way I and my small number of colleagues in North Carolina (because, in the 1980s, there were only a handful of neuropsychologists in our state) could get reimbursed for neuropsychological services. In turn, that effort resulted in the APA naming me their first representative to the AMA Current Procedural Panel in the early 1990s. Maybe I should share with you the vision of having Clinical Neuropsychology equally recognized and reimbursed as medicine (these are visions only a young and foolish person could have, however). The appointment to the AMA’s CPT Panel resulted in getting involved with the federal government’s Center for Medicare and Medicaid Services, the Mecca for all of health care. Interestingly, this appointment was largely secured with the help of then Senator Jesse Helms (R) of North Carolina. This story might reveal that there is so much behind the scenes and that, for better or worse, politics and economics drive a profession and a science. But alas, organizational histories, are rarely that interesting (except maybe that of Division 40 and, for that, I encourage you to read Puente and Marcotte, 2000—a chapter written for a book on the history of APA and edited by my undergraduate advisor, Donald Dewsbury). Besides, most organizations seem

to have memory deficits. Either way, I considered this type of information insufficient for a presentation of this importance.

Alternatively, maybe I could discuss more personal observations on colleagues in my specialty. One would think that in a discipline so closely linked with the brain and in pursuit of knowledge that we would expect to find large numbers of, if not all, individuals of great character. Indeed this turns out not to be true. Contrasting a large number of extremely dedicated, bright, and hard working professionals and scientists, there exists a small number of contentious, egocentric, and inflexible individuals who have forgotten that the Socratic method of questioning and the basic inquiry methods of Bacon and Newton apply to Clinical Neuropsychology as well as well as to other scientific pursuits. Mind you, this is clearly the case not only in North America but also in Latin America, Europe, Russia, and Africa (these are the locations where I have had some contact with clinical neuropsychologists). One wonders why in this search for truth and understanding, interpersonal conflict has to occur? Maybe, regardless of the value of the search, we are but human beings, fraught with the frailties we seek to understand. But, such human frailties make for better gossip than a presentation. So, not much more need to be said here.

Maybe, instead, I would talk about my prior reflections about Clinical Neuropsychology. After all, this year represents 25 years of my involvement in Clinical Neuropsychology, first while teaching functional neuroanatomy at St. George's University School of Medicine in Grenada, West Indies (and having to evacuate because communists from Cuba were taking over the island . . . seems to be a pattern I am familiar with) and now as a Professor of Psychology at the University of North Carolina Wilmington and a private practitioner. Maybe I would review my Presidential Address for the National Academy of Neuropsychology in 1990 and see how my youthful assessments and predictions have stood the test of time. And, in doing such a review, it would appear that indeed some things do not seem to change. The "Battle of the Boards" persists, the science of neuropsychology continues eroding, and the practice of the discipline continues expanding. How could one expect a specialty to change that much in a dozen years? And, indeed, if something is exciting, as Clinical Neuropsychology is, change is often the prevailing paradigm. Reflecting on reflections, as philosophically quenching an approach as this might be, seems, again incomplete. I am left with a yearning for something more.

Instead, I have chosen to write a personal letter to my grandchildren about things beyond the obvious that

I have learned by being a clinical neuropsychologist for 25 years. Something that I hope will be of value to them and, indirectly, to myself and maybe to my colleagues.

I formally started this letter in August of 2001 at the APA convention in San Francisco, California. An incident occurred on the way to the Division of Clinical Neuropsychology's Presidential Address by Jason Brandt—a particularly good address as well as President. That event spurred me to think more than usual, which is quite a bit as it is, about my chosen career and adopted specialty. Independent of that event but about the same time I recalled having attended a symposium by the late and noted neuroscientist, Wally Nauta, during the completion of my doctoral studies at the University of Georgia in the late 1970s. He gave an eloquent yet highly simple presentation summarizing his research, starting with studies in his own kitchen during World War II (I believe that he was Jewish and residing in Germany) to his later work at Johns Hopkins. In that talk, he emphasized that if he could explain his research and understanding of brain function to his grandchildren, it was worth something—otherwise, it was not of much value. Parsimony and simplicity were the hallmarks of good ideas.

So, having an unusual experience in San Francisco and interfacing it with a colloquium by Professor Nauta has provided the impetus for a letter to my grandchildren—that have not been born, not even conceived, and probably not even been considered (largely because your parents are 22, 18, and 15 at the time of my writing this letter). And, from this point on, I will use the active voice . . . as I am writing a letter instead of my grandchildren, I am writing a letter to "you," my grandchild.

Let me start this letter by explaining "the incident"—one that I am not sure anybody has heard before and, if so, they have heard but pieces of the story. My Presidential Address is, as Paul Harvey (a famous radio personality of our time), says, "the rest of the story."

I have been attending APA conventions for most of my adult life and have always enjoyed them a great deal (in fact, I even chaired the Board of Convention Affairs in 1993, the first meeting of the second centennial of psychology, a particularly exciting time in our field). The APA Convention is the one time that I get to experience all of psychology, not just Clinical Neuropsychology. I try to attend sessions on the teaching of psychology, the biological bases of behavior, philosophical issues, and the history of psychology, ethnic-minority issues, and the globalization of our parent discipline. From time to time, I also try to attend the lectures of well-known speakers in an area totally foreign to my work—always trying to learn and to expand my own (at times, limited) intellectual horizons.

But I have always had neuropsychology as my primary interest and I have devoted most of my time at these conventions to attend such programs. So, having been elected President (elect-designate is the correct title, if I recall correctly) and enjoying the division 40's program, it seemed entirely normal that I would attend Jason Brandt's address. Maybe I would arrive early for his presentation (an odd occurrence for me), even sit towards the front of the audience to show my support of his accomplishments as President and to be less distracted with such things as people arriving late. Well, I arrived late, really late . . . very flustered, sweating, and embarrassed . . . all because of this incident. I sat at the back of the large room and listened as best as I could. I did go up and congratulate him at the end of the presentation (we even took some photographs) since it appeared that it was an excellent talk—but, in reality, my behavior was a façade (though when I did eventually read the presentation, it was indeed excellent).

What was this incident? Your grandmother had asked me if she could accompany me to the convention in San Francisco, one of her favorite cities. Whereas this seemed like a simple request (and, in reality, such requests were typically never made in our relationship and family, things just flowed), it was a difficult one to consider. Here is why . . . your grandmother has secondary progressive multiple sclerosis. She has numerous problems; motor, sensory, cognitive, sometimes, emotional. I am going to share later on how some of these problems have come to express themselves and how they have impacted my thinking in Clinical Neuropsychology but for now let me focus on "the incident."

The two planes, 6-h flight from North Carolina, were really tough for her and, indirectly, for me. She arrived in San Francisco with significant fatigue, vertigo, and some difficulties in cognition. We tried to do some tourist activities, such as going to the Redwood Forest (a fiasco . . . the road was winding and she almost threw up . . . we barely left the tour bus). The entire stay was similar. By the end of the conference and our stay in San Francisco, we were both exhausted and frazzled. There was no question in my mind that this was the last significant trip she would ever take. And despite the fact that the Presidential Address was scheduled in a few hours, she suggested we take the cable car to Fishermen's Wharf as she had not visited the San Francisco Bay in a number of years. How could I say no to such a suggestion? During the cable car ride, her disease greeted us in a rare form, expressing its ugly self in the most ruthless fashion possible; your grandmother became extremely sick and I became inefficient and confused. This event turned out to be one of many times that MS decided to make life unfathomably impossible. How we managed

to make it back to the hotel and how I went subsequently to the Presidential Address, I will never know. That period of time, like San Francisco often does, has remained in a fog. It is one of those times that everything I had ever learned in Clinical Neuropsychology totally and completely failed me. In that instant, in the trolley to Fisherman's Wharf, crowded with pushy and pushing people and a cold, damp breeze, I came face-to-face with the limits of my specialty, maybe even of my character.

We returned to North Carolina, with equal difficulty . . . and ever since then I have been thinking long and hard about what Clinical Neuropsychology is really all about. If there was ever a time in which neuropsychology could have revealed to me its usefulness, it certainly would have been in this particular instance. A true experiment and an *in vivo* case history . . . a clinical neuropsychologist married to an individual with secondary progressive multiple sclerosis. This is the story, at least the public version, of how my specialty and my character were challenged . . . the story of how one clinical neuropsychologist has come to understand the limits of knowledge and of self, not by practicing, studying or teaching clinical neuropsychology (all which I have done and enjoyed immensely) but by living it, 24 h a day, 7 days a week.

For almost 25 years, I have had the opportunity to have seen different kinds of patients in different kinds of settings. For example, I have seen all kinds of neurologically affected individuals from the rarest disorders, ranging from agenesis of the corpus callosum to the actual split brain patients of Sperry, as well as the typical cases of dementia, head injury and stroke (probably the most common patients of clinical neuropsychologists). And, I have seen patients in a variety of settings, from our teaching hospital in Wilmington, North Carolina and my private practice (which have included both solo and group practices, both medical and psychological) to patients in institutions ranging from skilled nursing facilities to "super max" prisons. I even once did a dementia work up on the mother of a political prisoner in Cuba with armed soldiers watching. Although I am sometimes asked how many patients I have seen, in reality, I have no good estimate but I can tell you with great certainty that "a large number" can be used with confidence especially when one sees patients 5 days a week, close to 50 weeks a year for 25 years.

So, with equal confidence I can share with you that diagnosing is enjoyable, challenging, and routine. After all, if one does not become an expert after a quarter of a century of diagnosing patients, one never will. Then, it should come as a great surprise that I did not diagnose your grandmother's condition for a number of years. And, it was hitting me in the face on a daily basis. When she had a hysterectomy in 1989, she did not recover quickly—an

odd occurrence since the surgery was done by a friend of the family who took the greatest of care in our best estimate and your grandmother was in excellent medical condition, or at least I thought she was. Indeed she lost the use of her lower extremities for several weeks. Two neurologists missed the diagnosis as did several other medical professionals. There were other tell-tell signs along the ways and as early as in 1992 including how difficult our camping trip in 1992 across Europe culminating with the Olympics was for your grandmother. But it was actually my children, your parent (at the time the oldest child was 13) who called me discreetly from Greensboro, North Carolina (4 h away) during a junior tennis tournament to tell me that something was wrong with your grandmother. It was them, not me nor medical professionals, who diagnosed her. They correctly identified critical symptoms such as blurred vision, vertigo, gait problems, along with organizational problems and irritability (not in those words, but close enough to warrant emergent care). Sure enough, an emergency CT scan done back home showed the sclerosis active in her brain.

It comes as no surprise then that when I did share this sad news with a very small number of my colleagues, all offered their support and empathy and most offered suggestions and their expertise. I accepted Gerald Goldstein's, a long-time colleague and a pioneer in our field, on his kind offer of assistance. I traded a workshop at the University of Pittsburgh Medical School for a neuropsychological workup on your grandmother. In addition, Goldstein arranged a most useful contact with Rock Heyman, MD, a neurologist and multiple sclerosis specialist. She has subsequently been followed-up by them. However, I have to confess that outside the excellent neurological work by Heyman, the neuropsychological studies left a great deal to be desired. Mind you, it had nothing to do with Goldstein, nor his staff. Indeed the opposite is true. It had to do with the neuropsychological tests and diagnostic procedures. Not surprisingly, she "rose to the occasion," something that her long-time competitive spirit seemed to do in "high-stakes" social situations (maybe it had to do with her past experience as a competitive swimmer, tennis player as well as being a model). In either case, I lived and observed her difficulties in learning, memory, and organization as well as the irritability that surfaced unexpectedly. So, when the number of errors on the Category Test, or for that matter on all the tests revealed very, very little, if at all, I knew I was in trouble. And, I really felt I was in deep, when her treating neurologist in Wilmington called us one day around 2000 to share with us that the "disease must be in remission" since the MRI "had cleared up." At this point, she was sleeping up to 16 h a day and had vacated all of her typical

responsibilities . . . "cleared up," I wondered . . . what was that? "That" was another word for frustration, a constant companion in chronic neurological disease.

Both the neuropsychological and subsequent neuroradiological findings were initially perplexing, even disappointing. I learned, however, to eventually treat this information as data and to remove the emotional valence that is often attached to this (at least when the information is given to a patient or their loved one). I had come to understand that the relationship between neuropsychological and neuroradiological studies, at least in highly functional and well educated individuals, was weak, at best. How could, for example, how could I would ask myself, one obtain relatively clean neuropsychological evaluations and MRIs and still not be able to engage life as previously nor, in many ways, successfully.

Your grandmother was definitely in charge of our home and our family and she did it with ease and success. From being an officer in the PTA to being manager of the traveling soccer club, from running daily to playing competitive tennis regionally, from making each meal to taking care of household finances, from having an extended social network ranging from play groups to dinner parties, everything ran smoothly, efficiently, and with joy. All that has gone. She now stays home, rarely leaving the secure confines of a predictable life, tending to flowers, reading light novels as well as the Bible, briefly talking to her family, and she sometimes hosts, for very short visits, one of her friends. So, the question remains how could there be such drastic changes in her but have such benign neuropsychological and neuroradiological studies . . . And, again, how could it be that it took the children to diagnose her?

Although a significant percentage of my professional work in Clinical Neuropsychology has been diagnostic, I have a fair amount of patients that I have followed. Some, fortunately, I have helped to the point that their lives have, in some fashion, been restored so that significant societal involvement, for example, is realized. Others, less fortunately, need constant support and direction in making decisions throughout their lives. For these, I am "married" to them, as one of my right frontal lobe patients often tells me. And, yes, there are some that after a few sessions, one has to invariably conclude that there is really little to no hope. Hence, I have seen success, I have seen maintenance, and, although I prefer not to discuss too frequently since it is difficult to accept, I have seen failure. I should by now, one would expect, have a good working knowledge of what it means to have a significant neurological illness, at least in cognitive and emotional terms.

Well, how little did I actually know? I had incorrectly assumed that a comprehensive neuropsychological

evaluation (CPT codes 96115 and 96117; now 96116 together with 96118, 96119 and 96120) would produce the type of information necessary to appreciate the true workings of a neurological disease as well as the person with that disease. It turns out that this was fairly far from the truth. For example, problem solving, organization, and executive functioning deficits really are not that well measured by the Category Test, Wisconsin Card Sorting, the Tower of London and their intellectual cousins. And the MMPI is truly not the best way to understand emotional status. To complicate matters, the Beck Depression Inventory (BDI), also one of the most frequently used tests by neuropsychologists, presumably to address depression, measures direct and indirect symptoms. In other words, item analyses of the BDI indicates that an individual with fatigue, a hallmark symptom of MS, could endorse numerous items not because they are depressed, *per se*, but because the items correlate such symptoms as fatigue with depression.

Further, even if these instruments measured well what they were intending to measure (and, I am sure that many of you in the audience would suggest that this is indeed the case), they simply do not tell the entire story. It is somewhat grandiose to believe that in an 8 hour evaluation one could truly garnish the life of an individual with significant neurological illness. In some ways, third party reimbursement and a strong affiliation with medicine have both restricted our ability to spend time with the patient and have given us inappropriately based confidence in our conclusions and understanding of diseases and people. I wonder whether this is denial or neglect on our part. Let's assume it is denial, because after all, denial allows for the possibility of the truth to emerge.

Regardless, living with something like MS is so far from what my education, training, and experience prepared me for that it is truly hard to imagine. Let me provide some glimpses. In categories, let me share what my view is of what such a life is for the afflicted individual, for the spouse, for the family, and for friends. For the individual, life varies from trying to engage activity to running from such activity as fast as humanly possible. When somebody has been active, productive, and successful as measured by our White, upwardly mobile, American perspective it would only seem, as Newton has suggested, that when a body is in motion, its natural tendency is to stay in motion. What is perplexing, however, is that when bodies stay in motion, it punishes you. Continuing to do the car pool only complicates life. Attending to social functioning results in several days of fatigue. Tennis and running are historical activities. In fact, it has been years not only since she has played tennis but since she has seen the children play (the moving ball gets her dizzy and the competition gets her

sick). In fact, I do not recall that she has seen either of the boys play any high school tennis match. And, holidays, well, they are truly hell. As she told me last Christmas, "let me take a long nap . . . please wake me up in early January."

So, how many car pools, or meetings, or parties, or holidays does it take to come to the realization that in this illness "more is worse?" How have we conditioned ourselves to push hard, often, and past exhaustion, slowly inching forward our accomplishments and horizons? This new life requires exactly the opposite, "less is better" . . . you prioritize; you carefully choose your battles. Disconnection, saying "no," and restriction of boundaries and horizons become "healthy." You find comfort in the simple things, such as planting and tending to flowers, to eating a meal from start to finish without choking, to being with your family, even if significant problems are not being attended to. And, spirituality takes precedent; there is a great deal of comfort in God when things simply don't make sense. In making meaning of what does not on the surface appear meaningful, one becomes spiritual. I suppose one has too. The alternative is frightening. Of course, spiritual does not necessarily mean religious. In fact, I am not so sure that most religions, as practiced in the mainstream today, have great room for the severely afflicted. But God and spirituality becomes integral to sanity. Indeed, one has to accept such concepts. And the sooner one shifts from asking "why" to ask "what," the sooner successful adaptation occurs.

And the "what" is all about simplicity and effort. I suspect that in our egocentric and materially focused western professional lives, most would think of themselves as important, overextended, and wondering how will they get through the next day or week, project or activity. Maybe even we believe that meaning is derived by such overextension and the validity of such an over-extension is based on material productivity. In other words, the harder I work, the more I do, the more important and valuable my life must be. What if less was to become the definition of value. And, what if motivation was defined not as the over-exertion we are all so used to and comfortable with but what if it was defined as under or careful exertion. After all, every ounce of energy is carefully, carefully measured, used, and savored. Further, motivation is measured by effort not by output. Instead of finishing a day after having completed numerous domestic, professional, and personal tasks a day is successful if simply it has been lived with dignity and completeness, nothing more. Success is achieved by breaking down behavior, emotion, and thought into the simplest and most common denominator. After all, we have conditioned ourselves to believe that we are supposed to exercise for an hour at 6 A.M., get

the children ready for their activities, see several patients, produce interesting research, attend a meeting after work, run an errand on the way home, catch the news on cable, read a meaningful novel for a little while prior to making romantic and passionate love to our significant other before we obtain 7 h, no more, no less, of “quality sleep” in order to be rested for another “productive” day.

And, what is dignity? Well, it is getting up, hopefully before noon arrives. It is brushing your hair and teeth, and having breakfast before people have their lunch, and reading the newspaper, or most of it, or at least looking at it, before calling a friend or a family member; and, doing this before, fatigue sets in and it becomes too difficult to keep your eyes open, so that a nap is required. It is waking up reading the Bible, watering the plants, playing with the dog and hoping that the children and husband come home without too many stories or too much excitement because both are demanding and are not manageable. It is helping make a decision about dinner, whether it is in deciding whether it is take out or actually cooking something simple. And, it is sitting down in the living room hearing a story or two (no more than that, please) about the day before fatigue once more revisits and the bed is calling as a refuge from the demands of living. Dignity is about finishing a day having lived it to the fullest of one’s potential . . . and, potential has been significantly redefined. Further, it is about effort, huge efforts, efforts that I have not imagined could be possible, day in and day out. Effort in lifting heavy legs, pushing urine out when the bladder does not want to work, or of dealing with multiple conversations simultaneously. Every single activity requires so much effort. And, of course, staying in bed, which is what makes much sense when fatigue becomes your daily visitor, is psychologically and physiologically ill-advised. So, dignity is about finishing a day and exerting huge effort (more effort, mind you, than any us exert in our everyday, successful, professional, and material lives). And, what does this have to do with Clinical Neuropsychology? I don’t know . . . that is what bothers me.

In terms of interventions, there is ample hope, little data, and even less results. It would be probably not be such a good idea that one carefully read the design, methodology, statistical analyses and results of the studies that have produced the “miracle” cures of the interferon drugs and the chemotherapy that is often used when interferons don’t work. And, yes, we tried one, then another, and then two interferons simultaneously. The best results obtained were large welts where the injection sites were located. When that fail one could certainly turn to chemotherapy . . . of course, one has to be careful that it does not damage the heart (which it did in this case). The

simple and not so sophisticated interventions, as it turns out, have produced the most significant results. All those things we consider important in psychological health, actually produced measurable results. These include temperature and behavior regulation, lifestyle changes, shifts in cognitive paradigms and expectations, even simple relaxation techniques. And, let’s us not forget the massage therapy . . . that 1 h of extensive, yet short-lived relief. It is important to note that we have tried just about everything under the sun, including the traditional medical interventions (including, at this point consultations at four different institutions, at least half a dozen neurologists; as well as psychiatrists, occupational therapists, and, yes, we even tried a clinical psychologist who was more lost than we were). As to the alternative interventions, I have lost count but from algae and coral supplements to acupuncture and, I am almost certain, everything in between, has been part of the interventions. Again, it was the simple things that had the largest effects.

I indicated earlier that I would tell you how this affects the spouse, the family, and friends. Let me continue to share with you about how this situation affected me. Yes, I initially felt robbed (though to be honest that was, at most, momentary), later depleted and exhausted (it is hard to be “on” all the time), and now contended (how surprising life can be). While it is too personal to share much, let me provide some illustrations about my life. For example, I prided myself, despite being a Cuban, in having a relationship of equality. Tasks were evenly divided and problem solving was fluid, engaging, and, actually quite easy. I never made a significant decision, from financial to personal, without consultation with your grandmother. She, after all, was intelligent, emotionally balanced, and had a great “big picture of the world” view. However, slowly but surely, I have taken over everything— from paying the bills to choosing colleges for your parent. I took the children surfing before school and, then, to school, I attended their tennis matches, both home and away, I discussed with them everything under the sun, from sexual issues to career concerns—and, some, I would rather not say, I was woefully unprepared for. In fact, after the initial diagnoses, we instituted several “policies.” One was single-trial learning. With things changing so fast, and, in a negative direction, there was little room for trial and error. I suggested to the children that learning had to occur with one trial and, further, that the contingencies of failure were high, if not extreme. I believe some of my friends thought I had become autocratic, Nazi-like. I had become, simply put, pragmatic and realistic. Another “policy” was that of what I termed “pow-wows” . . . institutionalized meetings between the children and myself with the focus being how we kept the family moving forward as an integral and

successful unit. One of the first things we decided was that we “would protect mommie from the real world.” By that point we had come to realize how quickly and cruelly the world dealt with an “unproductive” member of society. Simply put, friendship sometimes is based on mutual-task sharing . . . if you can’t car pool or play on the tennis team, I can’t be your friend—at least these were the implicit messages that we often heard. So, one major thing that happened is that despite the fact that I had come to believe that I was an active father, at least relative to my peers; I become a much more involved parent. And, for that, I am most grateful. What special opportunities have emerged?

I learned from your parents what your grandmother needed. I also learned about how to be a partner to somebody that struggles each and everyday to finish that day with dignity, sometimes making my own pursuits seem trivial and inconsequential. Listening to her talk about flowers, about the dog (actually I think the dog thought he was a human; she shadowed her every move and, I believe he was a better diagnostician of her illness than any of her physicians were) or listening to passages of the Bible (her favorite was Psalm 23), became a way of life. Oh, yes, I wanted to discuss my own problems—whether they be complicated cases, recent research findings, or the external and internal “misunderstandings” of our specialty—but it was not meant to be. And, yes, I learned more about flowers, and about the Bible than I ever anticipated, probably even wanted- and, all of it was good and interesting and fulfilling. For those other “important” issues, there were colleagues and friends always eager, always there-ready to listen, support, and solve. (There is nothing like an illness to expose those friends who are truly interested and those who are along for the ride.) And, I learned how your parent (and our dog) diagnoses and rehabilitates; always watching for the most minute of changes (learning to diagnose in the middle of the night), always accepting, always there, never questioning, plenty of long looks, a great deal of touching, holding hands. I learned from your parent what she needed and wanted and, above all, it was a sense of understanding, of encouragement, and of love.

And as to how it affected your parent and my child, well it was interesting in more ways than I had anticipated. Lucas, the youngest, always said the same thing, “I never knew mommie well” so he took things at face value. In many ways, he was our model . . . never flinching, never reading more than necessary, always moving forward regardless of how bad things were, and they have been bad. And, our second child, Niki, as we called him at home (he was then 8th or so Antonio and this allowed for some distinction) took it hard. In his own way, the rebelliousness of adolescence mixed with the perceived

departure of an active mother resulted in an undesirable recipe for growth. Performance in school suffered (though it was imperceptible to the outside world or even to his grades), his rankings in junior tennis dropped from the top of North Carolina to well in the middle, and communication became choppy. With help from others, ranging from his high school tennis coach to our highly involved and supportive extended family, slowly but surely he came back and more, much more. He graduated close to the top of his high-school class and made All-State in tennis 3 years running. And, then there was Krista, the oldest and only daughter, who was emerging into womanhood when her mother became ill. How could she discuss boyfriend problems, the aggressiveness of other adolescent girls, college and career choices, and even how to dress and wear make-up? She managed to extend her circle of female influence, primarily to our extended family and circle of friends, and she managed to grow up quickly, very quickly. She has managed to balance being a daughter, a woman, and a caregiver simultaneously. She has grown up into a remarkable person who appears, at least at this point, interested in pursuing Clinical Neuropsychology as a career.

In many ways, your grandmother’s illness has been a “double or nothing” challenge. And although I am not entirely certain as to why, each of the children have experienced much more pain than any child should be subjected to in their lives, have managed to keep the suffering private, and, somehow, have emerged from this personal hurricane much like nature does after such natural disasters—with a greater maturity, appreciation and depth for life and living. A small indication of how it all fit together, the two oldest graduated this year—Niki from high school, Krista from college. And, your grandmother, as well as the extended family were all there to enjoy the success. The children have been changed forever and for the better.

The dynamics of an extended family are always perplexing and complicated. A serious illness appears to exacerbate those dynamics. The system becomes exaggerated and subclinical problems surface to the top. Not surprisingly, some family members flow and succeed in adapting and others disappear into thin air. What is surprising, however, is how this occurs. For example, those that support often do so in very idiosyncratic ways- such as in the form of taking the children on special trips or having them visit, calling frequently and without apparent cause, making unbelievable car deals when the children needed more permanent modes of transportation, and purchasing unneeded but always appreciated gifts. And, those family members that disappeared, their idiosyncratic disappearances were just as academically perplexing. For the sake

of preserving family integrity, it is best that those stories not be made public. Suffice to say, that enough supportive family surfaced to handle the demands of living successfully. If it was not for them, who knows how things would have turned out.

And, friends, oh . . . what would we do without friends. First, it is important to emphasize that unless you live with an illness of this sort, most people have no earthly idea what the ramifications are and, further, if you, as a family, choose not to share this information publicly, even more reason that a complete understanding of the situation is hard to come by. But somehow, friends come back, again, and again, and have for many years after the reasons for the friendship no longer are being served, and, in some cases, well forgotten. One of our neighbors, for example, keeps coming by, once a week or so . . . for brief periods, maybe 15 min (that is often all your grandmother can handle), with coffee and news of the outside world. And, how many times people have pinched hit specifically for me, I can't begin to tell you. How many times friends took your parent(s) to school, or to the beach to go surfing, or even to tennis tournaments away from home or how many meals have been cooked for us. I could not begin to count the acts of kindness that they have showered upon us. Most of my trips away from home (like the one to Toronto, Canada where I am delivering this presentation) were supported, in large part, by a friend providing assistance of this type. And, all those little notes to your grandmother that they wrote (and sometimes even to me or to us), meaningless on the surface, written in pretty script, on very expensive paper or overpriced greeting cards, saying "I am thinking of you," boy, oh boy, how much impact they have, nobody would ever know. Then there were special people, maybe a couple, more than friends, who were always there, especially when things got very tough. Somehow, they knew when those periods surfaced, even though those periods were not exposed to the outside world. And, yes, there are those friends, actually very, very few, who, like some family members, disappeared into thin air. Most, I believe, did so due to the natural evolution of friendships. For some, family and friend alike, illness is life in the raw . . . and, some, unfortunately, are not well equipped to handle such brutality. I understand and the initial anger that I and your parents had has turned to a kind of perplexing sorrow. They are, unfortunately, also similarly missing in the best of what life has to offer.

So, as part of my Presidential Address I was fully prepared to review research on cultural neuropsychology, to discuss the significant work of Sperry, to consider organizational histories and politics, even to discuss the personalities and influence of luminaries in my specialty.

But, alas, I decided instead to tell you about something more valuable, much more valuable—about the humanity of living under significant adversity.

I chose, instead, to write a personal letter to you, my grandchildren in the hopes that you, and I (maybe my colleagues) would come to understand about what lessons I have learned from a quarter century devoted to psychology's first specialty, Clinical Neuropsychology. And, in doing so, you would not only understand your intellectual heritage but the limits of my character and our chosen profession. In doing so, I trust that in the Socratic tradition that you will find comfort, solace, and challenge in the lessons that I have learned in Clinical Neuropsychology. And, in many ways, the most important lessons have come from learning about things that were never formally taught to nor by me. These lessons have come from learning about how an individual lives, day in and day out, with a neurological disease meant to rob someone of their person, of their dignity, and of their life. And, in being an unsuspecting student of neurological disorders, I have become aware of how little my specialty really knows about diseases and about people with such diseases as well as the systems in which they are involved. And, I have also learned about how exposure to the raw brutality of a neurological illness allows somebody to find more meaning in living than anybody could have imagined possible. And, in doing so, I have learned the importance of what Clinical Neuropsychology is all about. May you be so fortunate as to have the opportunity to understand the usefulness and limits of both your chosen career and of your own person without having to experience an illness of this type. But, if you do, may you have the courage and conviction that your parent and grandmother had to find meaning and dignity in such brutality.

PROLOGUE

Ever since my graduate training at Georgia I have been sensitive and interested in the concept of follow-ups, something relatively uncommon in clinical neuropsychology. However, in the particular case of the topic of this article, follow-up is more than sensitivity and an interest, it is everyday life. And despite this, the idea of writing a prologue had not occurred to me. However, two incidents prompted me to "pen" subsequent thoughts. One is that I had returned to San Francisco to work on a death penalty case in San Quentin. Lodging was downtown on the cable car line. One late evening as I was falling asleep the ubiquitous ringing of the street car bells elicited an unelicited classical conditioning response. Without hesitation or thought, I was instantly transported back to the last time

I had ridden one of them, with Linda. And sure enough, a flood of cognitions and emotions came forth with greater ease than I would have wished for. One of those is to compare and contrast the situation now with the one that had prompted the original writing of this article. Secondly, was the fact that as a Presidential Address for the American Psychological Associations' Division of Clinical Neuropsychology, such an address has been published every year since the founding of the division in the journal, *The Clinical Neuropsychologist*. I was not asked nor did I volunteer to publish the address. Indeed I was not particularly eager to submit the presentation. Whereas I was worried as to how they would peer-review such a paper (e.g., send it to experts whose spouse had similar problems, which turns out to be not-so-rare), other concerns of a different nature surfaced. So, after some thought (and, again, no consultation) I choose to provide a prologue to the story of Linda and to publish it as the last article to be published in my 10-year tenure as editor of the present journal, *Neuropsychology Review*. The prologue was written approximately 2 years after the Presidential Address.

Of some interest is the fact that all the issues that were raised at the beginning of the article remain relatively. For example, clinical neuropsychologists continue waging greater wars within the specialty than focusing their energies to battling pertinent outside and real issues (i.e., public policy issues). My research (e.g., cultural neuropsychology and coronary bypass surgery) and clinical work (ranging from volunteering at a free health clinic to death penalty cases) continue much along the same lines and some has enjoyed important support from several communities. The interest in Roger Sperry's work continues unabated and shows no signs of ebbing. And, of course, the continuing struggles with public policy issues remain very active (e.g., the development and valuing of new neuropsychological testing codes). However, what has taken most of my time, energy, and interest continues to be my focus on my family and wife.

As far as the children go, life has evolved. Krista has moved on to pursue a doctorate in psychology with an emphasis on clinical neuropsychology (surprise?) at Florida Institute of Technology. Antonio is in his third year at Flagler College playing on the nationally ranked tennis team and majoring in psychology (surprise?). And, Lucas struggles in a most effortless way to remain at the top of his high school class and his tennis game. All surf, have significant others and a strong social circle, outside of academic interests, and, by any benchmark that I could think of are evolving into the most competent and interesting adults a father could have ever wished for. I might add that the first people to have read the initial version, immediately after my presentation in Toronto, were them

(though Krista was in the audience along with some of my friends—a significant percentage who began crying, colleagues—almost all were extremely surprised, or at least their faces appeared that way and, for that matter, detractors—one whom fell asleep on the first row as I was reading the presentation). The extended family has remained as previously described, some intimately connected (thankfully) and others continue being incognito (thankfully?).

As to Linda, what can I say? She continues battling multiple sclerosis in a manner I never imagined possible. We do continue seeking medical assistance and support but in earnest such efforts remind me of the ones suggested by national MS societies—the major focus is hope. I honestly do not know what if anything tangible and empirical has been derived from any of the 40 or so medicines, three interferons (alone and in combination) and the new agent (Antegren) which was removed from FDA approved list days prior to beginning it and, of course, the countless medical and health appointments locally, statewide and nationally. It seems to me that outside of a curandero (i.e., a lay medicine man who practices health care within the scope of African-Cuban religion), nothing has been left to pursue. I still read all the articles in lay and professional publications about MS and from time to time I even participate (anonymously) in chat rooms involving MS. However, when it is all said and done, despite major progress, there is so, so little known about MS, especially from a neuropsychological, ecological, holistic and personal perspective that it is indeed discouraging. In essence, I have found little in traditional health care and science to be optimistic, though I prefer not to share this with Linda. After all, hope is an extremely important rehabilitative variable.

Her symptoms have continued progressing, quite unresponsive to all forms of traditional interventions. Social and family support, massage therapy, lifestyle modification and all the psychology one can muster up under such volatile situations are about the only things that have tangible and long-lasting results. Everything else is done as part of a protocol and as a means of preserving hope and a sense of effort (maybe to the “outside” world). In reality, however, what has worked the most is Linda herself. It is impossible to imagine the amount of courage, fortitude, and personal integrity that she manages to muster up each and every day, even each and every hour.

The motor symptoms continue marching on and the walker and wheelchair are regular companions. The walks by her down our cul-de-sac have shortened to our long drive way and even then, they rarely occur. The sensory symptoms bring daily new experiences and feelings sometimes in different parts of the body. Legs now “weigh

a ton each,” a good portion of her skin is numb, and the list goes on. Cognitive symptoms continue, unfortunately, to be part of the equation. As long as life is very simple, they are manageable; otherwise, problems arise. Emotional symptoms are, in some ways, most perplexing in that they seem relatively absent. By far her biggest complaints are vertigo and fatigue. Just about any novel challenge or extended task produces intense nausea and overwhelming fatigue.

Linda’s formula for handling all of this has been as surprising as the illness itself. Spirituality continues an integral part of her life despite less involvement from the organized religion she was one involved with (almost exclusively their choice). She reads the Bible and prays incessantly. By now she has prayed for the entire world’s problems though she seems to infrequently pray for herself. There is little question in my mind that the world is better off with her “watching” it. Courage and fortitude continue growing, something that seemed to me impossible. She manages to wake up each day, though later and later (often in the afternoon), and challenge the disease with a resilience and eagerness that makes me feel incompetent. There is no way anybody close to her can retreat into depression and despair. The opposite is most true, being around her empowers you. Indeed, her friends continue visiting regularly and for this very reason one tells me “I need to visit Linda for me much more than for her.” Her outlook for the future is brighter than anybody else that I know even those that seem to have everything going for them.

How all of this is possible I will never know. How science and health care, my chosen professions, have all but failed her is most disappointing. How members of her family have disappeared is actually a loss for them more than it is for Linda. Though I am sure that organizations (e.g., the PTA) and friends would have been served well with her presence and participation, they may be receiving greater benefits by her watching over them. And, of course, whereas one could lament the fact that her participation in the children’s life is so uniquely different (e.g., she has never seen Lucas play a competitive tennis match), she is there much more than any of us could have wished for. And despite I give the children all the credit, it is Linda’s quiet fortitude that gives them no option but to enjoy and succeed in life. And, as for me, again one could argue that I am losing a spouse in the most torturous manner possible, symptom by symptom over the course of a lifetime rather than weeks and months as most diseases manifest themselves. Yes, it has been years since she has

seen me present a paper, attend a social function, gone to the beach to watch me surf and so on. But what I have lost in the tangible I have gained many times over in the intangible. She has become more than a spouse, maybe a mentor, a beacon, certainly an angel. And maybe because of this, life has become more than bearable; it has become doable, maybe even enjoyable in a strange and most unexpected way. The horizons of life have been unbelievably stretched.

I have come to terms with the limits of my profession, of the family, and all those things one wishes for in a time of crisis. Most of all, I have come to terms with my own limitations, intellectual, personal, and otherwise. They are ample, more than one could have ever imagined. And, yes, I have come to terms with what life and nature has delivered. It has delivered a deceitfully packaged challenge of professional and personal magnitude of unimaginable proportions, maybe one that could only be lived to realize. But it has also delivered hope, courage, beacons, and solutions in ways that I could have never dreamed possible. Thus, in all of the faults and limitations and sadness and incompleteness of the disease process has arisen from its ashes a life full of opportunities.

Linda has provided challenges and avenues to understanding the mind that 50 years of clinical service and scientific research could never have come close. Her presence has been, in my estimate, the primary cause for the excellence and enjoyment of the three children. It could very well be that my career has been as successful as it has been largely due to her illness. And having a spouse actually evolved into having a mentor and a lighthouse in the middle of a hurricane we call life.

If my colleagues or the readers of this article do not think this is a story about neuropsychology, I say to you “you have not come to fully understand the brain and mind.” If the issue were that this is a story about trials and tribulations, I would rephrase it, as this is a story about successes and enjoyment. So, I finish this prologue and letter to my grandchildren (who have yet to be born) as a means to learn and understand the unexpected lessons that I have learned from 25 years in clinical neuropsychology. And, the greatest lesson did not come from the laboratory, clinic, or classroom; it came from underneath my very nose. Life was expressing itself in front of me while I was busy “studying” it. Linda and her illness forced me to understand what it meant to live. May you have the opportunity to learn the most important lesson of all enjoy and live life in whatever form it is presented?