

## 2. I Think It Begins with an "A"

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Over the years, perhaps since it first stroked its way into human awareness, aphasia has served as a vehicle for studying something—something other than itself. Its study has often served as a means to an end, less frequently as an end in itself. The world's scientific literature is replete with studies of aphasic patients who have been interviewed, tested, retested, overtested, stimulated, provoked, stroked, X-rayed, imaged, injected—and at times neglected as people. The data gathered from their detailed examination often are seemingly irrelevant *to them*. We hope the data have been, for the most part, relevant to somebody or some issue, but they seem only incidentally, or in the very long run, relevant to the patients and their relatives in their plight.

Perhaps aphasia's greatest popularity has been as a vehicle for discovering how the brain is organized. Are there language areas? Where? How are they related to each other and to critical sensory and motor systems housed around them?

At times, as in the last half of the 19th century, it seemed that *all* the famous neurologists were concerned with diagramming the brain, but not all were satisfied with this emphasis. You will recall that in 1926 Henry Head wrote about his frustrating experiences in localization. Now, 64 years later, the localization situation is better than chaos—his word for it—and nowadays we have lots of data about brain asymmetries, computer-like models of dynamic functional areas, and enlightened hypotheses concerning their relationship to one's understanding and use of language.

The handmaiden of localization has been the classification of aphasia into clinical types. Research studies have set out to relate clinical types to anatomical sites using various measurement methods. Failed attempts match successful attempts in number. A study that I'm sure was disillusioning to some appeared in 1984. Those productive workers in Aachen, West Germany, Klaus Poeck and his associates, entitled their study "Computed Tomography Localization of Standard Aphasic Syndromes" (Poeck, DeBleser, & von Keyserlingk, 1984). First they studied 32 patients with global aphasia with and without recurring utterances. Fewer than half of

these patients had the expected large perisylvian lesion, which would indicate infarction of the entire territory of the middle cerebral artery.

Even those patients with the most severe form of global aphasia who produced one and the same CV [consonant-vowel] recurring utterance and who had no language systematic elements left, . . . had very different lesion sites and sizes; in other words, they did not have a characteristic "strategically placed lesion," and their lesions were by no means the largest. . . . A cluster analysis was done on selected patients with Broca's aphasia, Wernicke's aphasia with and without jargon, mixed transcortical and transcortical sensory aphasia, and very severe and moderate global aphasia. [Someone had made these categorizations but with what degree of reliability and relevance to reality is not known.] No cluster of lesions included patients with only one aphasic syndrome. The majority of patients with jargon Wernicke's aphasia were found in the large postrolandic lesion cluster, and the majority of patients with very severe standard global aphasia could be found in the cluster of large perisylvian lesions. Even in those clinical groups the exceptions were remarkable. The remaining five syndromes were distributed over various lesion clusters. Lesions restricted to the basal ganglia could give rise to any aphasic syndrome. (p. 77)

They concluded,

The deficit theory of localization has not been strengthened by the *in vivo* localization of lesions in CT [computerized tomography] scans. On the contrary, one has recognized more negative cases than expected by the classic doctrine on the differential localization of aphasic syndromes within the left hemisphere. (p. 88)

So now what?

One must conceive of partial linguistic functions as related to neuronal networks, which are intricately intermingled in the language area. It follows that localization of function should be envisioned at the level of neuronal networks, the interruption of which in different places leads to similar symptoms. (p. 88)

Even if Poeck et al.'s study had documented a *close* relationship between brain site and clinical type, the issue is of minor importance to the patient and to most of us. The patient remains a unique individual with a unique brain who presents a unique mosaic of behavior that must be analyzed and then treated. The details of the patient's behavior and his or her improvement are not implicit in either the classification or the lesion.

The most recent exploitation of aphasia—not to say of aphasic patients—is linguistic. Linguists, psycholinguists, and neurolinguists have found a fertile field for discerning laws of language organization and dissolution

and their relationship to brain function. So patients have been bombarded with stimuli designed to reveal how they respond differentially to words and longer linguistic units when they are subjects or objects, present or past, simple or complex, direct or indirect, active or passive, abstract or concrete, salient or nonsalient, redundant or nonredundant, proper or common, singular or plural, embedded or unembedded, marked or unmarked, stressed or unstressed, affirmative or negative, interrogative or declarative, short or long, expository or narrative, and so on.

We would not deplore or make fun of the research that these anatomical, classificatory, or linguistic efforts represent, nor of the researchers who pursue their special interests. Goodness knows, we've been involved in some of it ourselves. The more we know about aphasia and all of its ramifications, the better off we believe we are. We are led to believe that it's better to *know* even if the utility of the knowledge is yet to be developed or is unclear or is highly restricted. The relevance and the ultimate applicability of the findings may become clear someday.

But some would rather shift attention away from the thing—aphasia—to the persons enmeshed in it—the patient who only inefficiently understands and produces language, the important other persons who constitute his or her environment, and the clinicians who help the patient grapple with the disability and guide him or her to even a partial triumph over it.

Aphasia is not an *it*. It is a he or a she or they. Aphasia is people—people who are more than vehicles for the study of something tangent to themselves, and who possess identity that we need to respect, sensitivities that we need to sense and honor, and potentialities for improvement that we need to value and exploit.

This is where, it seems to me, this organization has got it right. From its Porch-generated beginning until now it has put the focus on the patient—what the patient can do part of the time, what he or she can't do and when, how he or she can be stimulated to do better, and what obstructs that change.

What more can be done to understand and help this plural, nonneuter being?

For a start, how about this? Can we *decline* to study the overcomplicated anatomy and cleverly switch to the more lively realm of function? Although we have no evidence so far that any procedure other than language stimulation is clearly effective in facilitating improvement in aphasia, the studies of other types of intervention have been pathetically few and the numbers of subjects involved ridiculously small. We can count on one hand the studies of the effects of sodium Amytal. There is one study of meprobamate. I could not believe it when I saw that two papers presented this year reported on drug studies—the first I know of since 1977. In that year, Darley, Keith, and Sasanuma (1977) studied

comparisons between Ritalin (a stimulant and antidepressant), Librium (a tranquilizer used for the reduction of anxiety and tension), and a placebo, with each of 14 subjects serving as his own control in three treatment conditions. We found no differences between drugs or between drugs and placebo, but in our design there was unfortunately a common dosage for all and a total of only nine administrations. Too little, too quick, too restricted. We said that more such work should be done but we personally begged off: Lord preserve us from being the ones who had to do it.

Are there other drugs listed in the *Physician's Desk Reference* that are likely candidates for experimentation? Well, *yes!*

In Madison, Wisconsin, a man had been in a vegetative state, following an automobile accident, for 8 years. He was recently given Valium by a dentist in preparation for some dental work. He fell asleep for 5 minutes, awoke, and started to speak again: He answered questions and could say his name. After a second dose, he could say more, do arithmetic, tell where he used to work. Additional intravenous drug administration allowed him to remain lucid for 10 to 12 hours at a time. How did it all come about? Neurologists haven't been sure nor has the dentist.

Remember the Bible story about the parents of John the Baptist? Zachariah was *old* but was told he would produce a son. Luke reports that Zachariah, incredulous, asked: "How shall I know this for I am an old man and my wife Elizabeth is advanced in years?" The messenger said, "You will be silent and unable to speak until the day these things come to pass because you did not believe my words." Sure enough, he remained dumb, and sure enough, Elizabeth bore a son. The family celebrated and were ready to name him after his father, but Elizabeth said, "No—name him John. Ask his old man." They made signs to Zachariah inquiring what he would have him named. He asked for a writing tablet and wrote, "His name is John." And immediately his mouth was opened and his tongue loosed and he spoke, blessing God, just like in Madison. And fear came on all their neighbors—awe perhaps is the word, the same as in Madison. What ailed Zachariah, and how did he get over it? What unspecified divine surgery or injection brought about his startling recovery? We don't know.

What Darley, Keith, and Sasanuma should have done after completing our drug study and what we should do now is to team up with interested neurologists and pharmacologists and investigate the effects on nervous systems impaired in this way of a whole array of blood vessel dilators, mood alterers, and neurotransmitters, pharmacological agents that egg on the messengers or inhibit the inhibitors. Which patients of what ages, with what etiologies, behavioral characteristics, and language characteristics, and at what stage of recovery do better or worse on what language tasks in response to what dosages of what substances or combination of substances on what administration schedules? When we take a look in any

current neuroscience or pharmacology textbook, we are jolted by the realization of the level of sophistication at which research and application have arrived. We should strike up some professional friendships and—pardon the pun—get cracking together.

Another teammate we might seek out is the psychiatrist who knows and uses hypnosis. How pitifully little we know about its possibilities. We seem to consider it hokum—or we've heard that brain-damaged people are hard to hypnotize—and we've pretty much halted there. Hypno-therapy may be useful, as has been demonstrated, only in reducing motivational blocks in patients who are negative toward therapy—but how can we know?

What can we learn from experiments in memory? What facilitates retention and learning and relearning? What preconditions and what circumstances reduce forgetting?

I used to be mildly dismayed when colleagues spent their precious time studying largely hopeless patients with organic brain syndrome and Alzheimer's disease. But it has slowly dawned on me that the problems of language retrieval in aphasic patients, our "normal" gropings for the names of things and people, and the forgettings of the senile patient may share common features and dynamics.

When what's-his-name invited me to speak to . . . this group here in . . . uh . . . here . . . I told my wife about it. Edie's first response was, "I want to go too. I'm going, too." Her second was, "What will you talk about?" After a balk, I eventually replied, "Well, I think it starts with an A," thereby displaying the tip-of-the-tongue behavior common to lots of folks—you know, knowing what letter it starts with, how many syllables it has, whether it is long, medium, or short. At the time, I was wearing a favorite T-shirt on which was inscribed, "I know it all. I just can't remember it all at once." Frankly, of all the things I've lost, I miss my mind the most.

I urge study of the work of experimental psychologists in the area of memory, a deep dig into the data they have amassed, and a cooperative effort in relating their ideas and tools to the understanding and treatment of retrieval problems in aphasia.

We have a lot of good evidence now that language stimulation is effective in reducing aphasia. It works for many, and most should have the benefit of trying it. But I know families that have no inkling that our help might help their aphasic family members. This probably means that their doctors still display either of two deficiencies, both bad: either ignorance of the data or persistence, despite the data, in an old medical school bias that the aphasic condition is irreversible.

We must become better publicists of our work and accomplishments. Are we publishing in all the places we should—not just in *Proceedings* and in journals directed at one another but in national and state medical and special journals and journals for the general public?

About the need for public information: I'd like to report the state of soap opera sophistication regarding aphasia. I inadvertently heard an episode of *Guiding Light* on January 12, 1990. It turns out that this girl had been speechless for six years, displaying, according to one of the more knowledgeable characters, "something called aphasia." As the episode developed, I got the impression that they knew what they were talking about. But then it turned out that the etiology was, I think, new to the history of aphasia, namely, *rape*. And the apparent natural history of her alleged aphasia was atypical: A character confidently predicted, "If she doesn't get rid of her fears, she could get worse."

So despite the values of Aphasia Awareness Week just past, we should not only research and treat but write and talk to more and different people, not mainly to each other.

Now some words about the patient. I invite us to "see" the patient anew, to look at life and people as he or she does.

First, let's remind ourselves, and especially our students and interning clinicians, that our patients probably aren't as dense as they may seem. The fact that "they know it all but just can't remember it all at once" tells us to lighten up, go easy, appreciate that they have some insight, and acknowledge and draw on their retained skills. Let's remind ourselves that although the patient's retrieval system is haywire, the material to be retrieved is still in storage. Thank goodness we don't have to reteach the whole vocabulary and grammar system. It's all there; we stimulate the patient with some of it, and he or she comes back with more of it. It is apparent that treatment is not an "educational" process for reteaching lost bits of language via rote memorization but a stimulating process that facilitates retrieval of temporarily unavailable language.

Further, we realize that though they may not understand, speak, read, or write well, patients can "communicate." Spouses find this out and typically rate their aphasic spouses as less severely handicapped in communication than we rate them when we test them. They manage to transmit messages.

Second, we do well to remember that there is much about language that even the globally aphasic have been shown to retain. For example, they show recognition that a foreign language they hear is not their native language. They can distinguish between nonsense and meaningful language. They retain an appreciation of the relationship of stress to meaning, and are able to differentiate nouns from verbs where the differentiating characteristic is stress. They rarely evaluate grammatical sentences as ungrammatical. Like the rest of us, they demonstrate the tip-of-the-tongue effect. They can learn alternative modes of communication (for instance, using cutout paper symbols for words); this shows that central language processing is still possible at some level. They often continue to play cards, make change, derive from television what little meaning is

there. They continue to be vulnerable to criticism, impatience, anger, and neglect. They do not represent a language void, completely bereft of language-processing ability. They are not language idiots.

Third, the aphasic patient is a changing person whose language impairment is rarely immutable. Few patients exhibit no change at all. Almost all change some, and most change a great deal. It appears that the patient has a continuing capacity for improvement and that no door shuts, no time limit imposes itself on his or her potential.

Every reader probably knows these things well, and they cause us to take heart. But there's more to remember about the patient and where he or she lives. Let's visualize how the patient got to us. In his autobiographical book *The Youngest Science: Notes of a Medicine-Watcher*, Lewis Thomas (1983) begs us to *feel* for the patient.

The real problem is the shock of severe, dangerous illness, its unexpectedness and surprise. Most of us, patients and doctors alike, can ride almost all the way through life with no experience of real peril, and when it does come, it seems an outrage, a piece of unfairness. We are not used to disease as we used to be, and we are not at all used to being incorporated into a high technology. (p. 222)

Doctor Thomas relates a personal experience: Undergoing a bone marrow biopsy,

I discovered that being a patient is hard work. . . . It had never crossed my mind that it was, painless or not, so fundamentally unpleasant. That was my first personal experience with the kind of illness requiring hospital technology. Thinking back, I cannot find anything about it that I would want to change or try to improve, although it was indeed, parts of it anyway, like being launched personless on the assembly line of a great (but quiet) factory. I was indeed handled as an object needing close scrutiny, and intricate fixing, procedure after procedure, test after test, carted from part of the hospital to another day after day until the thing was settled. While it was going on, I felt less like a human in trouble and more like a scientific problem to be solved as quickly as possible. What made it work, and kept such notions as "depersonalization" and "dehumanization" from even popping into my mind, was the absolute confidence I felt in the skill and intelligence of the people who had hold of me. In part this came from my own knowledge, beforehand, of their skill, but in larger part my confidence resulted from observing, as they went about their work, their own total confidence in themselves. (pp. 224, 227)

Of course the nonmedical patient may have neither the benefit of this prior experience nor, perhaps, supreme confidence in his or her handlers.

Here is a patient now—against his will—survivor of several days of a medical roughhouse and none the happier for his “experience.” Experience, you know, is “what you get when you didn’t get what you wanted.”

With a nervous system stunned by stroke or surgery or trauma and a psyche stunned by his hospital factory assembly-line management, he is exhausted, feels lost, is perhaps unready for us. He is shocked to find that he has a language problem. Problems, M. Scott Peck tells us in his book *The Road Less Traveled* (1979), “evoke in us frustration or grief or sadness or loneliness or guilt or anger or fear or anxiety or anguish or despair” (p. 16). Now *there* is a bulging catalog of dismal states of mind, and our patient may very well have all of them.

Peck paints for us how hard it is for all of us to give up something precious. “In its major forms, giving up is the most painful of human experiences” (p. 67). People decline to continue psychotherapy, for instance, in order to avoid the pain of giving up parts of themselves, such as “personality traits, well-established patterns of behavior, ideologies, even whole life-styles,” smoking, drinking, being a big operator. Our aphasic patient has given up something precious, goodness knows, more precious than smoking or booze. He comes to us typically having experienced a series of losses of parts of himself, and “the feeling associated with giving up something loved—or at least something that is part of ourselves and familiar—is depression” (p. 69). Lest we have forgotten, Peck provides us with a list of what the patient has given up:

the agility of youth  
the sexual attractiveness and potency of youth  
the fantasy of immortality  
authority over his children  
various forms of temporal power  
the independence of physical health

and he faces in a sharp new way the giving up of “the self and life itself” (p. 72). According to Peck, “The pain of giving up is the pain of death” (p. 69).

Further, our patient, being aphasic, has special other experiences of lostness: the bewilderment of chatter about him that he does not totally grasp and bubbling ideas inside him that he can’t smoothly get out. I caught a glimpse of that bewilderment in somewhat different form a few weeks ago. I was out on our acreage north of Rochester—a piece of land some of you who have spent time with us in Rochester have seen in what you may have considered involuntary servitude, although I’m sure that looking back you realize that it was only a mild form of bondage. There I was, moving in a less frequently traversed part of the woods, when suddenly I didn’t know where in the woods I was. These particular trees



didn't look familiar, although I knew perfectly well that they were our trees; for heaven's sake, I had planted all these pines.

Oh, you'll say, he was just doing Henry Fonda in *On Golden Pond* to Edie's Katharine Hepburn. No, it wasn't like that. There was no panic, no unseemly behavior, no dashing about. But there was for a moment this weird feeling of lostness—something I had not experienced since the age of 7 when I got separated from my parents in Chicago's Union Station.

Then I got my bearings, found a familiar path, and was relieved not to be lost anymore. But I thought, an aphasic patient suffers that bewilderment repeatedly, even continuously; she isn't sure where she is, can't be sure she'll find herself whoever she is, and is disturbed by a happening strange and unfamiliar and dreadful.

So the patient faces problems that call for the courage to attack them, rather than succumbing to the hope that they will go away of their own accord. And, of course, that's where we come in as clinicians—to help patients muster courage, fight through their depression, and find that familiar trail again.

So now let's talk about the clinician, about us.

Peck (1979) has words about people who work with people: "Before the patient can risk major change, he or she must feel the strength and security that come from believing that the therapist is the patient's constant and stable ally" (p. 118). There must be a willingness to extend oneself and suffer with and over one's patients. Peck states: "It is impossible to truly understand another person without making room for that person within yourself" (p. 149).

Peck chooses to call this willingness more than just compassion or "a professional attitude." He calls it *love* and defines it as "the will to extend oneself for the purpose of nurturing another's spiritual growth" (p. 81). One must be "attracted toward, invested in, and committed to an object beyond the boundaries of self" (p. 94).

Genuineness is necessary. If the clinician behaves lovingly "because one is *expected* to behave in a loving manner—the clinician will be insensitive to the more subtle needs of the patient" (p. 139). "Love becomes demonstrable or real only through our exertion—through the fact that for someone we take an extra step or walk an extra mile. . . . Love is effortful" (p. 83). It takes work.

Peck suggests that we always prefer *not to work*. He goes pretty far on this, calling *laziness* man's original sin.

Each of us represents the whole human race; within each of us is the instinct for godhood and the hope for mankind, and within each of us is the original sin of laziness, the ever-present force of entropy pushing us back to childhood, to the womb, and to the swamps from which we have evolved. (p. 277)

Peck takes a personal view of the ubiquitous nature of laziness:

In the struggle to help my patients grow, I found that my chief enemy was invariably their laziness. And I became aware in myself of a similar reluctance to extend myself to new areas of thought, responsibility, and maturation. One thing I clearly had in common with all mankind was my laziness. (p. 272)

So Peck encourages us to become sensitive to our laziness and that of our patients—to fight it—“to take the more difficult path, the path of more effort rather than less” (p. 273), the road less traveled.

A critical ingredient of the clinical relationship is empathy—the capacity to feel what another is feeling. Lewis Thomas (1983) discusses how difficult it is to learn how patients feel; he talks about physicians but no less about clinicians in our field:

One of the hard things to learn in medicine, even harder to teach, is what it feels like to be a patient. In the old days when serious illness was a more commonplace experience shared round by everyone, the doctor had usually been through at least a few personal episodes on his own and had a pretty good idea of what it was like for his patient. . . . It is very different today. The killing or near-killing illnesses are largely reserved for one's advancing years. No one goes through the six or eight perilous weeks of typhoid anymore, coming within sight of dying every day, getting through at the end with a stronger character perhaps, certainly with a different way of looking at life. The high technologies which are turned on to cope with serious disease . . . are matters to be mastered only from lecture notes and books, and then by actual practice on patients, but very few doctors have more than an inkling of what it is actually like to go through such an experience. . . . Every young doctor should know exactly what it is like to have things go catastrophically wrong and to be personally mortal. It makes for a better practice. (pp. 220, 232)

One of my very first aphasic patients, early in my work at the University of Iowa, told me with astonishing insight that still flabbergasts me when I think about it today: “You've got to know what's going on in my head, even when I can't tell you.” The fact that he could and did verbalize this concept suggests that he saw a lack in me and in our clinical relationship, and he hoped to help me change so I could help him change.

I hope that all this is old hat to you. I just suggest that we teach our students and interning clinicians as much about *this* ingredient as about the ingredients of impeccable testing and scrupulous record keeping.

I would also like to emphasize that as clinicians we restimulate ourselves to remember those close to the patient: the spouse, the children and in-laws, the friends. A good friend and clinician who devoted time to the

study of aphasic patients, Robert Milisen, who is former head of the speech pathology program at Indiana University, learned about the adjustment problems of patients by using tape recorders under the bed to document the way they were bombarded wisely and unwisely by loved ones. He was so rash as to conclude (although his results were never published) that aphasia is not an organic disorder at all but a functional one—an artifact of the patient's outrageous treatment at the hands of family and clinicians.

As Wendell Johnson used to remind us, the patient always has more than two feet. When we define the victim of aphasia, we must include all the surrounding people, for everything becomes different, relationships are altered, roles are switched, feelings are heightened, and motives are questioned. However strong the love, patience wears thin, and the early naive ideas about what the problem is and how it will turn out may be displaced by disillusionment and despair. The family must be persuaded that the patient is not stubborn, demented, or mentally ill, and that it is not true that he or she is simply not trying. I recall the mother of a young aphasic patient injured in a car mishap with whom I had discussed the nature of her son's communication problem and the actions that would help him or would not help him. The moment we left the room, I heard her urge him to say something (perhaps it was "Tell Doctor Darley thank you"). "You can say it," she insisted. "Just try hard." So right away we had to go back in the room and talk about it again. Mom, if he *could* say it, he *would* say it. It's not a matter of his not wanting to. He really *can't*, and your urging him to try harder won't make it better, only worse.

We have to help the family understand that although the patient is different, he or she is still a person, who is not to be ignored. I'll never forget a scene I observed in the Omaha airport a few years ago. I can't for the life of me recall why I was in the Omaha airport, although I'm sure the reason was praiseworthy, but I clearly recall my view of a family group gathered happily to welcome back the son, a serviceman. Everybody was there, everybody was talking, everybody was happy. Grandma was there too. They had brought her along—sort of. Grandma had obviously suffered a stroke; she was ambulatory but severely aphasic. She was there in body, but nobody noticed her, nobody smiled at her, nobody talked to her, nobody held her hand, nobody hugged her. She was looking a bit panicky, isolated from her alleged loved ones as surely as if she had been encased in a Plexiglas soundproof booth.

So as super-clinicians we cannot forget our responsibility to the family. We may even solicit their help sometimes in administering therapy, and it looks as though sometimes they really help when they're instructed and monitored.

Finally, the medical practitioner is guided by the Hippocratic oath, and *we* should be too. Are you acquainted with what it sets forth as standards

for professional demeanor? I won't go over Hippocrates' list of behaviors *to avoid*, but I want to refresh your memory about one thing we are *supposed* to do. After appropriate obeisance to Apollo, Asclepius, Hygieia, Panacela, and all the gods and goddesses, Hippocrates swears to fulfill an oath and covenant, including the following: "To hold him who has taught me this art as equal to my parents and to live my life in partnership with him, and if he is in need of money to give him a share of mine." So, after this meeting, former students . . .

What else shall we say about the clinician? Only praise. Helen Keller said, "Although the world is full of suffering, it is also full of the overcoming of it." And there *you* are in the forefront of the overcomers.

You deserve a lot of joy and reward for what you do. The surprisingly quotable Calvin Coolidge stated: "No one has ever been honored for what he received. The honor was given for what he gave." And give you have. More honor to you.

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