Language and Medicine: Thinking and Talking About Alzheimer’s Disease

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Language is like a cracked kettle, on which we beat out tunes for bears to dance to, and all the while we long to move the stars to pity.

—Gustave Flaubert

The scene is familiar to most physicians: the doctor, the daughter, and the patient, a woman in her 80s. The history and physical are completed. The patient is old, and her body is beginning to fail. She is forgetful. At some point, the daughter asks the question: “Doctor, is this Alzheimer’s disease?” There are many possible answers. I never say “yes”; sometimes I say “no”; mostly, though, I am confused. My confusion stems from the fact that the daughter and I speak different languages. In all probability, the term Alzheimer’s disease means something very different to her than it does to me.

One theme common to all theories of language is the necessity for an agreed-on set of meanings shared by the speaker and listener, what professors of semiotics term a code (Eco, 1986). Without such a common code, communication is impossible.

In this essay, I will address three areas in which confusion about language hinders the practice of medicine: miscommunication between physicians and patients, miscommunication among physicians, and distortion of medical thinking. I will then return to consider the term Alzheimer’s disease in the light of this discussion.

Miscommunication Between Physician and Patient

There are terms in medicine that communicate very different things to doctors and patients. Arthritis is one such term. Joints tend to wear out. By age 65, an individual has virtually a 100% likelihood of having radiographic evidence of osteoarthritis in some joints (Gresham & Rothey, 1975). When a symptom, pain, coincides with radiographic changes, a diagnosis of arthritis is made, a diagnosis that a majority of older individuals have received from their physicians (Anonymous, 1990; Yelin & Katz, 1990).

Thus, the diagnosis of arthritis in an older person implies little to me. The x-ray usually was obtained to rule out more serious disease, such as fracture or metastasis. My job is to treat the pain and help restore or maintain function.

To many of my patients, however, arthritis is systemic illness, a malign force that once inside the body can strike anywhere (Goodwin, Black, & Satish, 1999). A pain at the base of the thumb today could be a crippling disease of the leg joints tomorrow.

Accordingly, with rare exceptions, I no longer use the term arthritis. As a word, it fails at its only task, to communicate a concept. Instead, I talk about “bad knees,” “bad hips,” and “bad shoulders.” These terms are far from perfect, but they come much closer to communicating to patients my concept of what is going on in their bodies.

There are many examples of this general problem in communication between doctor and patient. The term cancer produces similar difficulty. Cancer communicates deadly disease, a source of understandably great anxiety. Accordingly, it is imprudent to talk of “skin cancer” to a patient with basal cell carcinoma. A basal cell carcinoma is a potentially disfiguring skin problem, not a fatal illness.
It is important to note that questions of who is right and who is wrong about the “correct” meaning of words is irrelevant to a discussion of the utility of a language. To state that the patient misunderstands the physician’s use of the term arthritis is also to say that the physician has chosen the wrong words.

**Miscommunication Among Physicians**

Problems with language are not limited to communication between the physician and patient. They occur between physicians. When I was a junior rheumatology trainee, I shared a charting space in the clinic with our chief, a distinguished rheumatologist who had written a classic monograph on rheumatoid arthritis. One day as we each sat writing notes about our respective patients, he looked up and asked, “Which one is genu valgus—knock-kneed or bow-legged?” Twenty-five years later, I am still not always sure of the answer. That interaction represented a minor epiphany for me. Henceforth, I only described physical findings in words I understood and that there was a good chance that other physicians would understand. Varus, valgus, heliotrope—these and other obscure terms were banished from my vocabulary, as were such pretentious substitutions as upper extremity for arm and facies for face.

Questions about language are empirical issues, not theoretical ones. What matters is only what works, what communicates, not what is theoretically most elegant. For example, the metric system is potentially a much more powerful language with which to communicate various types of measurement than is the traditional English jumble of weights and measures. What about in real life? What percentage of practicing physicians know whether a serum sodium of 4.5 mmol or a serum glucose of 0.47 mmol is high, low, or normal?

**Distortion of Medical Thinking by Language**

The concept that language shapes and limits thinking was introduced by pre-Socratic philosophers (Wheelwright, 1966) and developed by Vico in the 18th century and by deMaistre in the early 19th century (Berlin, 1990). Because we think in language, and languages evolve as the products of specific cultures, then people from different cultures will think differently simply as a function of their different languages. In the 1930s, Benjamin Lee Whorf used the example of snow; the Eskimos have many different words for snow—blowing snow, wet snow, falling snow, etc., whereas the Trobriand Islanders have none (Carroll, 1964). Whorf postulated that this lack of words meant that the Trobrianders could not even think about snow, much less talk about it. Wittgenstein emphasized how language limits our ability to perceive reality. As described by Stanley Cavell, “Wittgenstein’s diagnosis is that we have, in part because of our illusions about language, fixed or forced ideas about the way things must be, and will not look and see how they are” (Cavell, 1979). Language allows for complex thought and consciousness. Similarly, language molds and limits thought (Burke, 1966).

Perhaps prostate cancer provides the clearest example in medicine of how particular choices about language predetermine thinking. The incidence of prostate cancer doubled, and radical prostatectomies increased almost fourfold in the United States in the years following the introduction of the prostate-specific antigen measurement as a screen (Potosky, Miller, Albertson, & Kramer, 1995; Shibota, Ma, & Whittmore, 1998). This dramatic increase in the use of radical surgery and other treatments for prostate cancer stimulated a substantial backlash from those who argued that, first, most prostate cancer detected by screening would not have produced morbidity or mortality, and second, none of the treatments for early prostate cancer had been shown to be superior to doing nothing (Etzioni, Cha, Fever, & Davidov, 1998). There is considerable emotion on both sides of this argument (Tannock, 2000). If the critics are correct, why do we perform so many radical surgeries? I would argue that the controversy is shaped by the language in which the debate is cast.

Let us return to the word cancer. Cancer is a fatal disease. Typically, as in breast, gut, or lung cancer, death will occur within a few months to years after diagnosis if no treatment is given. It is this very real inevitability of death that justifies the radical surgeries and other dangerous treatments used for these conditions.

But prostate cancer is not really like other cancers, particularly in the elderly population (Albertson, Hanley, Gleason, & Barry, 1998). A diagnosis of prostate cancer in a 70-year-old person has an impact on health similar to a diagnosis of mild congestive heart failure—a source of concern, perhaps a cause of future morbidity and mortality, but not the dread killer requiring an immediate and dramatic response (Albertson et al., 1998). My argument is that because we use the word cancer, we cannot apprehend the reality of prostate cancer—we cannot respond to it or think about it appropriately. What if another word were used? What if what we now call prostate cancer were named “Smith’s disease”? Might not the widespread acceptance of screening and treatment modalities have awaited evidence of their efficacy?

**Alzheimer’s Disease**

Let us now re-examine the term Alzheimer’s disease. My difficulty in answering the daughter’s question results from an integral of all three types of linguistic confusion described previously.

First, the term Alzheimer’s disease clearly means something different to me than to my patients and their families. The prevalence of dementia rises so steeply with age, with half of those over age 85 meeting diagnostic criteria, that it is difficult for me not to see “Alzheimer’s” in a 90-year-old individual as a “normal” result of aging (Anonymous, 1989; Goodwin, 1991). But, this is not what the term Alzheimer’s
From the text:

"Communicates to my patients and their families. To them, the term Alzheimer’s carries three messages:

1. It is incurable
2. It is progressive, steadily destroying the mind, the person, while the body remains
3. Most important, it is inherited.

Thus, if I reply that my forgetful octogenarian patient has early Alzheimer’s, I transform her from a great grandmother who repeats herself into something less than human, an object to be talked about, about whom decisions must be made. I have also made her the likely cause of a similar end for the daughter and her children. A dark force has been introduced into the family, something akin to how syphilis was viewed in the 19th century (Rosenkratz, 1979).

What does the term Alzheimer’s disease mean to physicians? We do not seem to be able to agree on the diagnosis. The pathognomonic findings of Alzheimer’s disease, neurofibrillary tangles and plaques, actually have very poor specificity for the diagnosis (Neuropathology Group, 2000). In addition, a recent study showed a 10-fold difference in estimates of the prevalence of dementia, depending on the diagnostic criteria used (Erkinjuntti, Ostbye, Steenhuis, & Hachinski, 1997). How can physicians talk confidently about Alzheimer’s if we cannot agree on the diagnostic criteria?

Use of the term Alzheimer’s disease also confuses thinking. We now know much about the pathophysiology of Alzheimer’s, and about the genetics and cell biology. These findings reinforce the concept of Alzheimer’s as a specific disease—a disease to be "conquered" (Butler, 1990; Fox, 1989). To this end, more than half of the budget of the National Institute on Aging is mandated for Alzheimer’s research. However, all aging processes have a basis in cell biology and genetics. By identifying these various processes with the names of specific diseases, aging becomes a series of conditions to be overcome. With enough scientific advances and sufficient understanding, aging will be wiped out, just like polio. How can we think clearly about aging if the terms we use force us to see it as a disease rather than a natural process (Blumenthal, 1999; Goodwin, 1999)?

Conclusion: A Modest Proposal

What about a moratorium on the use of the term Alzheimer’s disease for individuals older than 80 years? Instead of Alzheimer’s disease, what about late-life learning disability? It communicates the major issues of dementia. In most older patients with mild to moderate dementia, the predominant cognitive defect is the inability to incorporate new information. This is most often referred to as short-term memory, but is actually learning, or acquisition of new knowledge. Late-life learning disability also suggests the best way for patients and their families and physicians to view this disorder—as a disability. When Alzheimer’s becomes late-life learning disability, we will be able to think more clearly about the condition; the interventions will become more obvious. People with difficulty learning new things function best in stable environments. In addition, late-life learning disability allows for continued communication and continued personhood. Men and women with mild-to-moderate dementia still may be a source of much wisdom in a family, calling on their life-long experience. Their store of information is often considerably more extensive than that of their younger relatives. Will the condition progress? In all probability, yes. In some cases, it can result in severe dementia, a truly dehumanizing illness. However, most individuals over age 80 who meet diagnostic criteria for Alzheimer’s-type dementia are not severely demented. Most of these individuals will die of other causes before severe dementia occurs, just as most older patients diagnosed with Smith’s disease by prostate-specific antigen screening will die of other causes before the condition becomes troublesome.

Let me be clear. This is not an “anti-science” essay. Removing the disease label from old age should not impede basic research. A detailed understanding of the different phenomena involved in aging may very well lead to interventions that prevent or slow those processes. I fully expect that the current efforts in dementia research will produce therapies that postpone or reverse declines in cognition. The price for this progress, however, need not include the medicalization of aging. Restricting the term Alzheimer’s disease to those under age 80 should allow all of us to think and talk more clearly about the cognitive changes that affect the majority of men and women who are fortunate enough to achieve very old age.

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