

Political Correctness

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POLITICAL CORRECTNESS (PC) exists for a reason but can be taken to extremes.

Political correctness affects all spheres of human interaction. Let us consider PC in the medical sphere. It was not long ago that we used terms that even those who now mock PC might possibly find repellent, or not, unless the terms were used to describe their family members. The word "idiot" is a good place to start. In Fyodor Dostoyevsky's novel *The Idiot*, the protagonist suffered from epilepsy, just like Dostoyevsky himself, a syndrome which earned the sufferers the label "idiots." Perhaps it was a kind, euphemistic term back then, but I doubt it. It was a term used in Western medicine that had more than one meaning. For example, there were syndromes, like Amaurotic Idiocy, now called Tay-Sachs disease, among others, that incorporated the term in the official labels given to certain diseases. In a sense, then, the term was technical, rather than jargon. It is easy to see how the "technical" term idiot was picked up by the lay public to mean what it does today. One might contrast the idiot concept of epilepsy with that of Pharaonic Egypt, where epilepsy was considered a "royal disease," because it occurred in the royal families due to a genetic disorder, resulting from inbreeding.



Mongolian idiot was the technical term for what we now call Down syndrome, or trisomy 21. These people were sometimes called "Mongoloids" or "Mongols," as if physiognomy signaled an ancestry, which, in turn, was linked to a denigrating term both for the patient and for people from

Asian countries.

In my own subspecialty of neurology, movement disorders, terms like "reptilian stare" and "simian posture" were also used in a "technical" way. People with Parkinson's disease, who had a fixed, staring expression, a hallmark of the disorder, were described as having a reptilian stare. The posture in PD is stooped, hence, "simian," or "ape-like." There didn't used to be a lot of PD patients because they died early, and people didn't live as long as they do now. And doctors held a more prestigious and august status than they do now so that patients and families were probably less likely to complain. How many middle-aged people would like to hear that their parent, or they, themselves, were diagnosed with PD because of their reptilian stare and simian posture?

Hysterical, of course, referred to histrionic and flighty behavior ascribed to movement of the uterus.

Midget, retarded, and spastic are terms that are widely used in denigrating

fashion for the non-ill. They have been, for the most part, discarded, although retardation and spastic are technical terms that, like idiot, describe syndromes. For example, spasticity is the term to describe an abnormality of muscle tone in which the tone is increased in a way that depends on the rate at which the limb is moved, and is associated with increased deep tendon reflexes and possibly positive Babinski reflexes. Describing a "spastic paraparesis" is a useful distillation of clinical findings. Calling someone "spastic" or "a spaz" is a denigrating term that presumably means clumsy, and is used only as an insult. We describe degrees of retardation, mild, moderate or severe, depending on one's score on tests of intelligence, including ability to understand, recall and solve problems.

Not long ago it was common to use the word "senile," which should simply mean elderly, as synonymous with dementia. This is presumably because it is tied to the term, "senile dementia," which had meant Alzheimer's disease. The word has continued to be used in isolation to mean demented, conflating dementia and old, implying that dementia is part of the aging process.

Dumb is an interesting word. Its real meaning is mute, but has been extended, probably because not talking is sometimes interpreted to mean stupid, to mean just that, stupid. "Struck dumb" means "struck speechless," but "dumb bunny," "dumb fool," etc. means

lacking in intelligence or thoughtfulness.

I agree there is sometimes an over-emphasis on political correctness. For example, I am not in favor of describing short people as “height handicapped.” And, perhaps because I’m a neurologist, I do not object to the term mental retardation, with the modifiers mild, moderate or severe, although just as much information would be present with the terms of mild, moderate or profound “learning impairment” or “intellectual limitation.”

The real issue is what the affected population experiences when we use the term. I recall giving a talk to medical students and, in talking about the epidemiology of a disorder, mentioned its prevalence in Asian countries. A student of Asian descent thanked me after the talk for using the term Asian instead of “Oriental.” I had purposely used the term because someone had told me that

“Oriental” was often interpreted as denigrating. While I had no idea at that time that this was the case, it seemed quite clear to me that there would be no reason to use the term, “Oriental” anymore, except for describing certain forms of art, despite the fact that I had never heard the term used in a disparaging sense.

In the early days of clinical genetics, scientists used to coin terms they thought “cute” for a gene they isolated, for example “sonic hedgehog.” However this caused problems when a family would be told that their child has a disorder, holoprosencephaly, caused by this gene, and the terminology was quickly reined in.

Being PC simply means being sensitive to the meaning of the words we use. In *Alice in Wonderland*, Humpty Dumpty states that “when I use a word, it means exactly what I choose it to

mean.” This is not correct. Words can hurt. We should use the terms based on how they are perceived, not how we think they should be perceived. Using denigrating labels, even if they seem not insulting to the user, is a way of distancing ourselves but also reduces how patients think they are valued. ❖

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Grateful Patient Philanthropy (GPP) raises ethical concerns among doctors

HERBERT RAKATANSKY, MD

RECENTLY TWO DOCTORS, separately, expressed their concerns to me about being asked to participate in soliciting patients for donations to a hospital.

Medicine has evolved into a “big business” model in which doctors are regarded by management as “revenue centers.” The revenue comes mostly from patient care but asking doctors to solicit grateful patients to donate is becoming widespread. In fact, this endeavor now has a name: Grateful Patient Philanthropy (GPP). These programs are based in the institutional development office.

GPP is big business. In 2012, \$28.12 billion was donated to health organizations, 75% from individuals (not all of them patients). The median cost to raise a dollar is \$0.31. Gifts vary in size from \$400 million given by Denny Sanford to a health system in South Dakota to gifts of a few dollars. Funding for hospitals is perilous at best and likely to get worse in the next few years. In the current political climate philanthropy is an essential component of our health care system.

You might ask how administrative staff even knows about who has been treated. Changes in HIPAA regulations (in 2013) allow institutional fundraisers to learn the name, address, age, gender, date of birth, dates of health care service, treating doctor, outcome information and health



insurance status. This information permits the development office to accurately evaluate patients as prospective donors.

A disclosure of this policy must be included in the “notice of privacy practices.” And to quote from the regulations: “Each fundraising communication made to an

individual under this paragraph, a covered entity must provide the individual with a clear and conspicuous opportunity to elect not to receive any further fundraising (solicitations).” Thus, patients cannot prevent the development office from accessing the above information and may opt out only after the first contact has been made

A recent survey indicates that 95% of institutions without a GPP were planning to start one and 88% of institutions with a GPP were planning changes and/or additions. By far the most popular change was “*increasing focus on physician/clinical staff engagement in patient referrals.*” No GPP programs considered downsizing! A 2016 report on GPP noted that the two top “insights” about GPP were 1.) Grateful patient programs are in growth mode and 2.) Today’s top investment: engaging physicians in referral.

Are doctors good at fundraising? The answer is “it depends.” In a randomized trial, 51 doctors were taught soliciting

techniques either by email (14) or lecture (18) or personal coaching (19.) The doctors in the coaching arm generated \$219,550 during the study. No gifts were received in the email or lecture arms.

The primary ethics issue is whether solicitation by doctors violates the fiduciary relationship between a doctor and a patient. The fiduciary nature of this relationship has been well established in US case law. The introduction of a third

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party may “destroy the trust that the patient has that the doctor’s only goal is the health of the patient.” The fiduciary duty of a doctor to his patient is a legal obligation as well as a moral commitment and violations may trigger legal consequences. The doctor’s moral and fiduciary obligations are in peril if solicitation alters clinical decision-making.

We know that gifts from drug companies to doctors be they small, such as items with a nominal value, e.g.: pens, etc. or of moderate value such as meals, influence doctor’s clinical decisions. And, despite the evidence, doctors generally believe that others might be influenced, but not themselves.

So what is a doctor to do?

It seems obvious that a doctor should not be reimbursed a percentage of donations for soliciting patients. Indeed only 3% of 405 doctors surveyed in 2015 reported such payments. However, financial reimbursement is not the only reward doctors may receive for successful fundraising. Public recognition, titles such as “champion fund raiser,” etc. and other non-monetary rewards may be very powerful. Napoleon opined: “A soldier will fight long and hard for a bit of colored ribbon.”

The AMA Code of Ethics states that doctors should:

“Refrain from directly soliciting contributions from their own patients, especially during clinical encounters.”

It is important to note that although non-caregivers in the hospital may have access to some data, they cannot access diagnoses or treatment details. This information is protected and may be divulged to the development office only with specific permission from the patient.

It is critical to assure patients that the quality of their treatment is in no way related to their willingness to make donations. But the erosion of trust may be subtle and doctors must be sensitive to this issue.

Doctors who engage in fundraising by giving talks about research or clinical programs to groups of patients at special events are in little danger of damaging their relationship with a specific patient. The closer one gets to an individual doctor soliciting an individual patient, the more danger there is of compromising trust. In a study of 20 Johns Hopkins’ doctors, 18 identified misuse of the doctor patient relationship as the “most significant ethical concern” in GPP.

Best practice GPP guidelines issued by management consultants state that a doctor, the more prominent and respected the better, be identified as a “physician champion” and be recognized by other doctors as the leader of the GPP effort.

Management consultants have suggested that department chairs might lead GPP in their discipline and receive a bonus if defined fundraising goals are met. Might fundraising then unwittingly influence the clinical or academic status of department members or reward “special treatment” of VIP patients by department members?

Other management best practice suggestions include visits to patients (while in the hospital) by administrative or development personnel.

Another ethics issue is Justice. Might scarce resources be more available to donors?

Thus, I would advise the two doctors whose concerns spurred this response that policies concerning physician participation in GPP should be determined not by “management” alone. To protect us all from ethical lapses and thus protect our patients, a comprehensive discussion of GPP policies should be initiated by the hospital ethics committee and then be considered by the entire medical staff of the hospital. Joint ownership (management and doctors) of GPP policies might accomplish a dual purpose. Patients would be protected by an ethically appropriate GPP and involvement of all medical staff members might increase enthusiasm for GPP and produce increased funding by grateful patients. ❖

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