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Why The Federal Government Wants To Redefine The Word 'Cancer'

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The federal government wants to reduce the number of Americans diagnosed each year with cancer. But not by better preventive care or healthier living. Instead, the government wants to *redefine* the term "cancer" so that fewer conditions qualify as a true cancer. What does this mean for ordinary Americans — and should we be concerned?

On July 29, 2013, a working group for the National Cancer Institute (the main government agency for cancer research) published a paper proposing that the term "cancer" be reserved for lesions with a reasonable likelihood of killing the patient if left untreated. Slower growing tumors would be called a different name such as "indolent lesions of epithelial origin" (IDLE). Their justification was that modern medical technology now allows doctors to detect small, slow-growing tumors that likely wouldn't be fatal. Yet once patients are told they have a cancer, many become frightened and seek unnecessary further tests, chemotherapy, radiation, and/or surgery. By redefining the term "cancer," the National Cancer Institute hopes to reduce patient anxiety and reduce the risks and expenses associated with supposedly unnecessary medical procedures. In technical terms, the government hopes to reduce "overdiagnosis" and "overtreatment" of cancer.

It is true that some patients wrongly view the word "cancer" as the equivalent of a death sentence and become overly distraught. This can cloud their judgment when they most need their full rational faculties to make sound medical decisions.

But while there are legitimate scientific and medical questions about the proper definition and classification of any disease (including cancer), we must be careful that that any redefinition won't be used for inappropriate political purposes. Given the increasing government control over US health care, how the government defines medical terms can have serious economic and policy implications.

For example, the definition of a "live birth" has become important in discussions over health care policy. Many on the political Left cite the supposedly high infant mortality rate in the US relative to Europe as one of the failures of the US health system.

But Dr. Bernadine Healy (former director of the National Institutes of Health and of the American Red Cross) has noted:

"The United States counts all births as live if they show any sign of life, regardless of prematurity or size. This includes what many other countries report as stillbirths. In Austria and Germany, fetal weight must be at least 500 grams (1 pound) to count as a live birth; in other parts of Europe, such as Switzerland, the fetus must be at least 30 centimeters (12 inches) long. In Belgium and France, births at less than 26 weeks of pregnancy are registered as lifeless. And some countries don't reliably register babies who die within the first 24 hours of birth.

Thus, the United States is sure to report higher infant mortality rates. For this very reason, the Organization for Cooperation and Development, which collects the European numbers, warns of head-to-head comparisons by country".

Likewise, the definition of the beginning of "pregnancy" has implications for the abortion debate. Does pregnancy begin when the sperm fertilizes the egg? Or when the fertilized egg becomes implanted into the lining of the uterus ("taking root" in the mother, so to speak)?

Some medications allow the egg to be fertilized, but block implantation. Depending on the definition of pregnancy, this can mean the difference between the drug being considered a form of birth control (if pregnancy starts at implantation) vs. causing a chemical abortion (if pregnancy starts at fertilization).

Similarly, the American Medical Association recently voted to declare obesity a "disease." But as Cato Institute health care analyst Michael Tanner noted, "the AMA's move is actually a way for its members to receive more federal dollars, by getting obesity treatments covered under government health plans."

With respect to the definition of "cancer," downgrading some conditions as no longer being "cancer" can and will used to justify reducing "unnecessary" screening tests (e.g., mammograms for women between ages 40-49). Mammograms can now detect the condition known as "ductal carcinoma in situ" (DCIS), which would no longer be called a cancer under the new proposal.

However, a certain percentage of DCIS lesions can and will progress to clear-cut cancers. As Dr. Barbara Monsees and Dr. Carol Lee wrote in a letter to the *New York Times*:

"The dilemma with breast conditions like ductal carcinoma in situ has no easy answers. Some cases will never advance while others become life-threatening. The problem, however, is not in the name; it is in the fact that it is not possible to know which cases will progress and which will not…

Overtreatment of possibly innocent disease is definitely a problem, but the solution is not simple. The problem is with the depth of understanding of the biology of these lesions, not with the name".

Furthermore, the terms used to describe abnormalities to patients can have a significant effect on their decisions, as illustrated in a recent study (summarized below):

"The researchers presented 394 healthy women with 3 clinical scenarios that described a diagnosis of DCIS using 1 of 3 terms: abnormal cells, breast lesion, or noninvasive breast cancer.

Each woman reviewed all 3 scenarios and the accompanying set of treatment options (surgery, medication, or active surveillance) and outcomes (chance of developing invasive breast cancer or dying). The information was identical — except for the terms used to describe DCIS.

When DCIS was described as noninvasive breast cancer, 53% (208 of 394) of participants preferred a nonsurgical option".

However, when the DCIS was described as a breast lesion, 66% (258 of 394) preferred a nonsurgical option, and when it was described as abnormal cells, 69% (270 of 394) preferred no surgery.

In other words, the terminology used swayed patient decisions, even when patients were given identical data about their treatment options and outcomes.

So what does this mean for doctors and patients?

Doctors should stay current on the science of early cancers, so they can best counsel their patients about their options.

However, doctors should not adopt a rigid one-size-fits-all approach in deciding whether or not to use the word "cancer" when discussing these emotionally difficult diagnoses with patients. Instead, the discussion should be tailored to each patient, based on their individual tolerance for the risks of overtreatment vs. undertreatment. (Several of my colleagues use the term "precancerous" when describing DCIS to patients, which conveys an appropriate degree of urgency without being too alarmist.)

Patients should perform due diligence if they learn they have a precancerous condition or an early cancer. They should stay calm, discuss all their options with their doctor, seek second opinions as necessary, and perform their own independent online research.

Patients should also be aware of any emotional and cognitive biases associated with the word "cancer." They should work to keep their focus on the objective facts of their disease and associated treatment options, including the risks of overtreatment vs. undertreatment. Above all, patients should decide based on their own personal values and preferences. They shouldn't let the government wrongly "nudge" them one way or another by its preferred terminology.

I don't believe the individual scientists arguing for a redefinition of cancer are driven by inappropriate political motives. But government will soon account for 66% of health spending and is aggressively seeking to limit health expenditures. Hence, the government may have a vested interest in definitions that err towards undertreatment, rather than overtreatment. We must

remain vigilant against any attempts by the government to use language as a tool of covert rationing.

Dr. Milton Wolf, a practicing radiologist who cares for patients with DCIS warns against this Orwellian possibility:

> "Health care rationing takes many insidious forms but perhaps the most immoral is for the government to wage a public relations campaign designed specifically to dissuade patients and doctors from seeking available cures for cancer. They scheme to rename cancer, not to cure it, but to deny it exists. These government rationers have calculated that rather than actually treat patients with cancer, it's cheaper to simply keep them as calm as Hindu cows right up to the very end".

"Cancer" is a powerful word. Hence, whoever controls the definition of that word wields tremendous power over patients. Ordinary Americans should stay vigilant to ensure this power isn't wrongly used against them.