The word “cancer”: how language can corrupt thought
Antiquated nomenclature is misleading and needs to be revised

Barbara K Dunn medical officer¹, Sudhir Srivastava chief², Barnett S Kramer director³

¹Chemoprevention Agent Development Research Group, Division of Cancer Prevention, National Cancer Institute, Bethesda, MD 20892, USA; ²Cancer Biomarkers Research Group, Division of Cancer Prevention, National Cancer Institute; ³Division of Cancer Prevention, National Cancer Institute

Cancer screening is a double edged tool. Screening may reduce the risk of death from the targeted cancer, as in screening for cervical (Papanicolaou test, human papillomavirus testing), colorectal (fecal blood testing, endoscopy), breast (mammography), and lung (low dose helical computed tomography) cancers. Unfortunately, other cancer screening tests in common use are of questionable value or have none at all. These include cancer antigen 125 (CA125) and transvaginal ultrasound for ovarian cancer, serum prostate specific antigen for prostate cancer, and chest radiography for lung cancer.

Regardless of their usefulness, most cancer screening tests carry an underappreciated harm—overdiagnosis, the detection of non-lethal lesions that meet the histologic criteria for cancer or cancer precursors. Two factors are required for overdiagnosis: a reservoir of occult indolent lesions and activities leading to their early detection.¹ Diagnostic scanning may also show incidental findings (“incidentalomas”), another source of overdiagnosis.² The mere labeling of such indolent lesions as “cancer” or “carcinoma in situ” is a potent driver of thought and action because it incurs fear.

The concept of early detection of disease is intuitively appealing, so screening tests are often embraced by health professionals and the public well before the balance of benefits and harms has been determined.¹ The concept is further reinforced by misleading personal experience. Even a useless screening test that advances the date of diagnosis without changing the date or cause of death will appear effective to patients. In addition, tests that lead to overdiagnosis of non-lethal lesions will artifically inflate five or 10 year survival and “cure” rates with cases that did not need to be cured in the first place.⁴

The perception of benefit is powerful, and calls for screening asymptomatic people without strong evidence are not new, dating as far back as 1861.⁴ In the realm of cancer, Johns Hopkins surgeon Joseph Colt Bloodgood issued a call to action in 1924: “Deaths from cancer would be practically eliminated . . . if persons afflicted sought medical aid immediately upon the discovery of a foreign growth in any part of the body.”⁴ A common strategy has been to inculcate a sense of vulnerability to cancer and then offer hope.⁴ Fueled by the persuasive language and sound bites of marketing, cancer screening has become a core public health message.⁵

The crude screening tools of the past have been supplanted by increasingly sensitive tests that may amplify overdiagnosis. We are now able to dip far deeper into the reservoir of latent “cancers” and “precancers” using blood tests, a range of imaging devices, and probes. Slower growing—and even completely non-lethal—lesions have progressively diluted the pool of clinically aggressive lethal tumors that dominated cancer diagnoses of the past. The observed temporal increases in early stage disease without equivalent declines in later stage disease provide evidence that overdiagnosis is common.⁶,⁷ The word “cancer” is used to describe an ever broader spectrum of behavior; but the word retains its fearsome quality, sometimes corrupting thought and action. Labeling hurts. Healthy people are quickly converted to cancer patients, and toxic interventions are offered and accepted. Radical prostatectomies are done for non-progressive, screen detected, low grade tumors. Even non-invasive lesions contain words implying the inevitability of “cancer” (for example, ductal carcinoma in situ), and bilateral mastectomies are performed for localized in situ lesions without firm evidence that death from breast cancer is reduced. Personal expenditures mount, sometimes exacerbated by unemployment after diagnosis. Personal bankruptcy increases among patients with cancer. Overdiagnosis can sometimes have lethal consequences, triggering biopsy related sepsis, postoperative death, or even suicide.⁸ Are there solutions? In 2012 the US National Cancer Institute convened a group of experts to consider remedies to this overdiagnosis-overtreatment conundrum.⁹ Attendees suggested that antiquated nomenclature should be revised, reserving “cancer” or “carcinoma” for lesions likely to progress if untreated, and raising thresholds for defining “abnormal.” As Otis Brawley of the American Cancer Society has stated, “We need a 21st-century definition of cancer instead of a 19th-century definition of cancer, which is what we’ve been using.”¹⁰ Terms like “cervical intraepithelial neoplasia” and “epithelial tumors of low malignant potential” for lesions of the ovary are one solution. In a similar vein, a 2009 National Institutes of Health
“state of the science” conference proposed removing “carcinoma” from ductal carcinoma in situ, by changing it to something like “ductal intraepithelial neoplasia.” Another suggestion is the reclassification of low risk lesions as IDLE (InDolent Lesion of Epithelial origin). Research on predictive molecular tests that distinguish non-progressive lesions from life threatening ones is another high priority, as shown by the National Cancer Institute funded Early Detection Research Network. For example, molecular patterns of screen detected and symptomatic breast cancers differ, with concomitant differences in progression. Molecular profiles might therefore be able to distinguish between clinically meaningful cancers and overdiagnosed cases. In some clinical situations, such as in active surveillance of prostate cancer and Barrett’s esophagus, molecular patterns in serial biopsies can be linked to prospective follow-up. Finally, a counter to the intuitively seductive notion that earlier detection of cancer is always better is needed. Physicians, patients, and the public should be made aware that screening has both benefits and downsides, including overdiagnosis. Balanced messages can convey the idea that overdiagnosis and resulting overtreatment are not rare in an era of increasingly sensitive screening tests. An important goal is not to discourage screening tests of known efficacy, but to maximize the benefits of such tests and minimize their harms.

Competing interests: We have read and understood the BMJ Group policy on declaration of interests and declare the following interests: None.

Provenance and peer review: Commissioned; not externally peer reviewed.

The opinions expressed in this manuscript represent the views of the authors and do not necessarily reflect official positions of the United States federal government or of the National Institutes of Health.


Cite this as: BMJ 2013;347:f5328

© BMJ Publishing Group Ltd 2013