Ductal Carcinoma In Situ: Should the Name Be Changed?

By Steve Graff

Speakers at the National Institutes of Health state-of-the-science conference on ductal carcinoma in situ (DCIS) in September set out to assess critical areas in the field and ended up with a range of research recommendations: Improve risk stratification of patients, look closer at biomarkers, and compare the effectiveness of treatment methods.

Surprisingly, though, after an unexpected flurry of comments from participants, panel members also decided to give emphasis to the topic of a name change not only ended up in the final conference statement but also spurred calls for another meeting, now in the planning stage, to discuss whether omitting “carcinoma”—what some call the “anxiety-producing term”—is appropriate.

“The panel in general felt that it was very important for the medical community at large to at least consider the terminology of DCIS through the elimination or the inclusion of the word ‘carcinoma,’” said panel chair Carmen Allegra, M.D., chief of hematology and oncology at Shands Cancer Center at the University of Florida, Gainesville. Allegra told reporters at a press briefing, which centered mostly on the change, that “This will be the topic, hopefully, for future panels to wrestle.”

Opinions from such a panel could vary widely. Proponents of a name change say it will ease anxiety and ultimately help women make a more rational decision when it comes to treatment. But those who are ambivalent about a change point to the lack of data. A clarification to a name typically occurs when new information about the biology of the disease surfaces. For DCIS, where more research is needed, invoking a psychosocial argument—where research is even more scant—could make the change seem unwarranted. Others argue that resources could be better spent or that excluding the word “carcinoma” downplays a possibly life-threatening disease.

“It’s a very, very complex issue,” said Worta McCaskill-Stevens, M.D., the state-of-the-science conference planning chair and program director at the Division of Cancer Prevention at the National Cancer Institute, in an interview. “But in terms of quality of life and communication, I think we can do a better job of coming to some consensus.”

Shortly after the conference, the American Cancer Society (ACS) and McCaskill-Stevens started to talk about potential education and communication strategies to address the issue. “We are actively talking,” said McCaskill-Stevens, referring to the ACS and the Office of Medical Applications of Research at NIH, among others. “I’m not quite sure what the outcome is going to be. I’ve gotten some individual responses from some of the participants at the conference. But it’s really been mixed.”

The groups would like to see a meeting convene this spring or summer, which would presumably include oncologists, pathologists, radiologists, surgeons, and representatives of government agencies, advocacy groups, and patients.

What is DCIS?

Otis Brawley, M.D., chief medical officer of ACS and an oncologist who is in favor of the name change, argues that the medical community can take better care of patients both emotionally and medically if there is a better name. “I think there is a huge amount of confusion,” he said. “I’m much more concerned that we are scaring a whole host of people that have ductal carcinoma in situ who make rash decisions because it’s called ‘carcinoma’—decisions that they wouldn’t make if it was more adequately described for what it truly is.”

In DCIS, abnormal cells have accumulated in the breast duct but have not spread to other tissues in the breast. Although the disease’s natural course is not well understood, scientists agree that some cases may develop into invasive breast cancer or spread to other parts of the body, and some may not. However, because which types of DCIS (the disease is ranked from low- to high grade) may progress is unclear, making treatment decisions can be difficult for patients and providers. Many factors affect choice of treatment, including a woman’s age, family history, grade, and how widely the cells appear in the ducts. But treatment of some sort is still recommended, be it a lumpectomy, full radiation, or systemic hormonal therapy. The disease has a 10-year survival rate close to 100% when treated (although some argue that many of those cases would never have progressed in any case). Some women even opt to have the healthy, opposite breast removed prophylactically.

As it stands now, the name represents a spectrum of pathology, from indolent disease to potentially progressive disease, according to Arnold Schwartz, M.D., Ph.D., professor of pathology at George Washington University Hospital in Washington, D.C., who sat on the state-of-the-science conference panel. In other
words, the name isn’t restricted to one disease approach or treatment method.  
“If you want to use a euphemism, then that’s fine,” said Schwartz, who is neutral about a name change. “But you still have to do three things: Be descriptive, engender communication, and be true to the biology.”

Speaking from a pathologist’s perspective, Schwartz said he does, however, have a problem with the knee-jerk reaction that the current name is a bad one. Technically, it’s correct. “When you are saying ‘carcinoma in situ,’ what you are saying from a pathologist’s point of view, looking at the morphology through a microscope, is that the very same cells that you see in invasive cancer have morphologic similarities to the noninvasive cells within the duct structure,” he said.

This viewpoint suggests that DCIS is a precursor to cancer.

Brawley, who doesn’t see it the same way (“DCIS is a pre-neoplastic condition and not cancer,” he argues), is more concerned with overtreatment. The introduction of mammography has caused a substantial jump in breast cancer diagnoses over the years. What’s more, about 25% of all mammographically detected breast cancers are identified as DCIS. Women now more than ever are faced with the question of what to do next after being diagnosed with the disease. This puts a lot of them in the hot seat, according to Brawley, who worries many will be given or will seek unnecessary treatments.

“I’m hoping [a new name] changes the number of women who hear that they have DCIS who immediately are frightened and scared as they shouldn’t,” said Brawley. “That is what I am trying to prevent.”

Some studies have shown that many women overestimate the chance of recurrence when diagnosed with breast cancer, and that they develop anxiety because of it. However, data supporting the idea that women undergo unnecessary treatments specifically because of the word “carcinoma” are practically nonexistent. Many turn to the 2008 study by Ann Partridge, M.D., of the Dana–Farber Cancer Institute in Boston and colleagues (see J. Natl. Cancer Inst. 2008;100:243–51), which found that many women with newly diagnosed DCIS have inaccurate perceptions of the risks and that anxiety is particularly associated with these inaccurate perceptions. The authors did not look at any specific words or how these perceptions affect treatment decisions, but they did recommend such studies. They wrote: “. . . future research should assess the impact of altered risk perceptions on treatment decision making among women with DCIS and test interventions to ameliorate anxiety . . . .” Many researchers who attended the conference, including McCaskill-Stevens and Schwartz, agreed that this area of research needs more attention, whether they change the name or not.

“There are insufficient data to tell me that women are really offended, troubled, scared by the term [carcinoma].”

Other Name Changes
Diane Solomon, M.D., who is in NCI’s Division of Cancer Prevention and the driving force behind the Bethesda System, the reference guide for cervical cancer diagnoses first introduced in 1988, describes the name changes for cervical cytology as an evolution. “As we’ve come to understand more about the pathogenesis—and as management has changed—the terminology has been shaped,” she said.

The cervical precancerous condition, where abnormal cells replace the full thickness of the epithelial surface of the cervix, started out as cervical carcinoma in situ (CIS). Lesser abnormalities were considered mild, moderate, or severe dysplasia. These terms were then replaced by three grades of cervical intraepithelial neoplasia (i.e., CIN 1, -2, and -3), in which CIN3 encompasses both severe dysplasia and CIS. (The CIN terminology is still used today for cervical tissue diagnosis.) As researchers learned more about the human papillomavirus, biological understanding became the basis for changes to the terminology. Most human papillomavirus infections regress spontaneously, but sometimes persistent infections become associated with precancerous cell changes. To reflect this, the Bethesda System introduced the terms “low-grade” and “high-grade squamous intraepithelial lesions” for reporting cytologic findings on Pap tests.

“[This situation] is similar, but definitely not the same,” said Susan Reed, M.D., an obstetrician–gynecologist at the Fred Hutchinson Cancer Research Center in Seattle, during the conference press briefing. “For the understanding of the biology and the classification of cervical precancers, I think we’re far ahead of where we are with the breast tissue. . . . we were able to move to a classification system that makes sense and removed the word ‘carcinoma’ from those precancerous lesions.”

Although it’s true that new scientific findings fueled discussions for name changes for cervical cancer, the psychosocial aspect also played a role, according to Solomon. “Having the term ‘carcinoma’ there . . . did engender a lot of anxiety. In some cases, if it’s a low-grade lesion, you don’t want women to be overly anxious because you want to sometimes manage these things very conservatively, because often they will go away on their own,” said Solomon. “You want to use terms that convey risk but don’t elicit so much anxiety that women seek overtreatment. You [also] still want them to come back to what’s appropriate follow-up treatment.”

At the conference, an internist in the audience addressed the panel, stating that he liked the term “carcinoma” in the phrase. He argued that it gets women to listen more closely about a disease that could in fact develop into something worse.
“That’s a valid argument,” said McCaskill-Stevens. “If we were to change the name, we don’t want women to become too complacent.”

Barbara Brenner, director of Breast Cancer Action, an advocacy group, said it doesn’t make a difference if it’s called “neoplasm,” “carcinoma,” or even “the bad disease.” Conversations about treatment have to happen regardless of what the disease is named, she argues. “I know there is a great deal of anxiety with DCIS, but I don’t think the anxiety would be lessened by calling it something else, because at the end of the day you still have to talk to someone about what to do about it,” said Brenner. She said it’s the treatment that’s scaring women, not the name. In Brenner’s view, the medical community should allocate any resources being spent on the name change to improving risk stratification of patients because the real issue is not knowing whom to treat.

“It’s a nonpriority,” said Brenner, who said she would attend the name-change meeting if the opportunity presented itself. “This is a silly discussion. I understand why doctors want to have it, but it’s not going to help women one iota.”

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