Challenges in Ductal Carcinoma In Situ Risk Communication and Decision-Making
Report From an American Cancer Society and National Cancer Institute Workshop

Ann H. Partridge, MD, MPH1; Joann G. Elmore, MD, MPH2; Debbie Saslow, PhD3; Worta McCaskill-Stevens, MD, MS4; Stuart J. Schnitt, MD5

In September 2010, the American Cancer Society and National Cancer Institute convened a conference to review current issues in ductal carcinoma in situ (DCIS) risk communication and decision-making and to identify directions for future research. Specific topics included patient and health care provider knowledge and attitudes about DCIS and its treatment, how to explain DCIS to patients given the heterogeneity of the disease, consideration of nomenclature changes, and the usefulness of decision tools/aids. This report describes the proceedings of the workshop in the context of the current literature and discusses future directions. Evidence suggests that there is a lack of clarity about the implications and risks of a diagnosis of DCIS among patients, providers, and researchers. Research is needed to understand better the biology and mechanisms of the progression of DCIS to invasive breast cancer and the factors that predict those subtypes of DCIS that do not progress, as well as efforts to improve the communication and informed decision-making surrounding DCIS.

CA Cancer J Clin 2012;62:203-210.

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Introduction
At the National Institutes of Health (NIH) State-of-the-Science conference on ductal carcinoma in situ (DCIS) held in September 2009, it became evident that there were a number of issues related to the communication of risk to patients regarding the disease.1-4 Recommendations were made for more research to be done in the area of DCIS risk communication and for the development of decision aids and strategies to integrate them into clinical practice. The Consensus Panel Statement also concluded: “Because of the noninvasive nature of DCIS, coupled with its favorable prognosis, strong consideration should be given to remove the anxiety-producing term ‘carcinoma’ from the description of DCIS.”2

In consideration of these issues, the American Cancer Society (ACS) and National Cancer Institute (NCI) convened a workshop in September 2010 to review available evidence and issues regarding DCIS risk communication and decision-making and to identify directions for future research. Invited participants included a small group of clinical and basic scientists, advocates, and communication specialists (Table 1). Patient-provider communication and informed medical decision-making surrounding DCIS diagnosis and treatment, psychosocial outcomes of women with DCIS, and consideration of changing the nomenclature were addressed. The primary goal of the ACS/NCI workshop was to review what is known about these issues and to develop recommendations and strategies to improve them. A secondary goal was to discuss what we know about the association between DCIS nomenclature and distress or confusion, and the pros, cons, and feasibility of changing the nomenclature for DCIS and to identify areas where more information is needed.

Conference participants heard presentations by experts, followed by question-and-answer sessions and group discussions. The speakers included Worta McCaskill-Stevens, MD, MS; Ann H. Partridge, MD, MPH; Joann G. Elmore, MD, MPH; Karen Sepucha, PhD; Stuart J. Schnitt, MD; Fattaneh A. Tavassoli, MD; Umberto Veronesi, MD; Neeraj Arora, PhD; and Mary Lou Smith, JD, MBA. This article summarizes the key points from presentations and discussions in the context of the current literature from the ACS/NCI workshop as well as future directions to address the issues raised.

1Associate Professor, Department of Medicine, Harvard Medical School, Dana-Farber Cancer Institute, Boston, MA; 2Professor of Medicine, Adjunct Professor of Epidemiology, University of Washington School of Medicine, Section Head of General Medicine, Harborview Medical Center, Seattle, WA; 3Director of Breast and Gynecologic Cancer, American Cancer Society, Atlanta, GA; 4Program Director, Division of Cancer Prevention, National Cancer Institute, National Institutes of Health, Bethesda, MD; 5Director, Anatomic Pathology, Beth Israel Deaconess Medical Center, Professor, Department of Pathology, Harvard Medical School, Boston, MA.

Corresponding author: Ann H. Partridge, MD, MPH, Dana-Farber Cancer Institute, 450 Brookline Ave, Boston, MA 02215; ann_partridge@dfci.harvard.edu

DISCLOSURES: Dr. Elmore serves as a medical editor for the nonprofit Foundation for Informed Medical Decision Making.

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A brief overview of the NIH State-of-the-Science conference was presented to set the stage for the discussion.\textsuperscript{1,2} For the purposes of discussion, the following definition of DCIS was used: DCIS is the replacement of normal ductal cells with a spectrum of abnormal cells confined to the breast ducts. The diagnosis has increased dramatically in the era of mammographic screening such that DCIS is now diagnosed in approximately 50,000 women in the United States alone annually.\textsuperscript{5-7} Research has revealed that DCIS is a term that encompasses a heterogeneous group of lesions.
with a variable natural history and risk of progression to invasive breast cancer. The natural history and risk of progression to invasive disease has been studied in women who were found to have DCIS on retrospective review of breast biopsies originally categorized as benign and who, therefore, underwent no more than a diagnostic biopsy. In these studies, which included primarily cases of low-grade DCIS, up to 40% of women were diagnosed with invasive cancer in the ipsilateral breast with follow-up of more than 30 years. Data such as these have historically been used to justify aggressive local therapy for the disease. Current standard treatment options for DCIS include excision followed by radiation, wide excision alone, mastectomy, and tamoxifen after excision, with or without radiation. Among women treated with breast-conserving methods, there remains a broad range of local recurrence rates, although this rate is generally lower than in the setting of invasive disease. Of note, approximately 50% of local recurrences following breast-conserving treatment will be invasive cancers and 50% will be DCIS (Fig. 1).

Risk stratification among women with DCIS has been an area of active research for more than 2 decades but remains challenging. There are currently no clinical factors, histopathologic features, or molecular markers singly or in combination that permit the reliable stratification of risk of either invasive or noninvasive recurrence for individual patients. The role of molecular markers and gene expression signatures to identify patients at risk of future events of DCIS and invasive breast cancer is evolving, but the clinical usefulness of these tests is at the present time uncertain. Consequently, there is controversy about the optimal treatments for women with DCIS. Overall, however, women with DCIS have a very favorable prognosis and a diagnosis of DCIS is not likely to affect a woman’s survival. Furthermore, there has been concern about the overtreatment of DCIS, particularly small lesions that might not have ever become clinically evident. Thus, addressing the problem of suboptimal communication and the potential for poor-quality decision-making and psychosocial outcomes is of great clinical importance.

**Knowledge and Communication About DCIS**

Evidence suggests that DCIS is not a disease with which most women are familiar. In a cross-sectional survey of 479 US women in 1997, only 6% reported that they had heard of DCIS and only 7% agreed that there are “some types of breast cancer that grow so slowly that even without treatment they would not affect a woman’s health.” Among women who are diagnosed with DCIS, there is a lack of understanding of the disease entity, particularly with regard to the noninvasive nature and whether or not it is “cancer” or could spread to other places in a woman’s body and become life-threatening. For example, in a letter to the *BMJ*, a patient with DCIS understandably bemoaned the fact that during one appointment with her physician, she was told both that she did have cancer and that she did not have cancer. Women’s confusion is potentially compounded by the use of the term “carcinoma,” as this implies for many women that they have invasive breast cancer. In addition, treatments recommended for DCIS such as mastectomy, partial mastectomy followed by radiation, and hormonal therapy are also often recommended for women with invasive disease, possibly leading women to think of DCIS as being the same as invasive cancer. However, there are no rigorous data available on the reaction of women to the use of the term “carcinoma,” as this implies for many women that they have invasive breast cancer. In addition, treatments recommended for DCIS such as mastectomy, partial mastectomy followed by radiation, and hormonal therapy are also often recommended for women with invasive disease, possibly leading women to think of DCIS as being the same as invasive cancer. However, there are no rigorous data available on the reaction of women to the use of the term “carcinoma,” as this implies for many women that they have invasive breast cancer.
There is very little available information regarding physicians’ perceptions and communication strategies in caring for women with DCIS despite the substantial evidence that the management of DCIS is strongly related to physician recommendations and varies substantially nationally and internationally. A cross-sectional survey of 151 US physicians who care for women with DCIS revealed heterogeneity among them regarding the terms used to describe DCIS when speaking with patients and management approaches for the disease. The majority of these physicians rated the emotional distress that women generally experience when diagnosed with DCIS as high and perceived the treatment decision-making process to be quite difficult for these women. Most (78%) also indicated that the DCIS decision-making process was as difficult (36%) or more difficult (42%) than that for women with invasive breast cancer. Finally, only 63% of respondents indicated that a diagnosis of DCIS posed little or no risk to a woman’s overall long-term health. A survey of 296 health professionals in the United Kingdom involved with the treatment of patients with DCIS confirmed diverse perceptions of the disease, difficulty explaining DCIS to patients, and heterogeneity in the terminology used. It is likely that the clinical heterogeneity and uncertainty about the natural history of DCIS (particularly for any given woman), as well as the controversies surrounding optimal treatment, contribute to the heterogeneous management approaches and likely some physician discomfort with the disease. Further evaluation of the effects of physician attitudes, communication strategies, and management approaches for women with DCIS on patient outcomes is clearly needed.

Risk Perceptions, Anxiety, and Quality of Life in Women With DCIS

Given the confusion among patients about the entity of DCIS, and heterogeneous views among providers, it is not surprising that many women with DCIS are anxious about their disease and overestimate the risks they face. In a recent cross-sectional survey of 144 women diagnosed with DCIS in Australia, many women expressed both misunderstanding and confusion about DCIS and the associated risks, and desired more information about their breast disease. In this study, 73% of women described their disease as early stage breast cancer, and only 19% of participants were aware that not all women with DCIS will develop invasive breast cancer. Approximately 60% of women thought DCIS can metastasize and 27% were unsure about this. Furthermore, approximately one-half of the women in the study expressed high decisional conflict when considering treatment options.

In a large prospective cohort study of US women with newly diagnosed DCIS (N = 487), a substantial proportion of participants harbored inaccurate perceptions about the breast cancer risks they faced, including both local and distant recurrence. For example, approximately 25% of women perceived at least a moderate risk of DCIS spreading to other parts of their bodies at the baseline, 18-month, and 5-year follow-ups. Increased anxiety was significantly associated with inaccurate risk perceptions.

Several studies have also found that women with DCIS have similar risk perceptions and anxiety compared with women with invasive breast cancer. In a cross-sectional study of 228 women with either DCIS or invasive disease, women with DCIS perceived that they had essentially the same risks of local recurrence, distant recurrence, and death compared with women with invasive cancer. In a prospective study of 549 women with newly diagnosed early stage breast cancer, including a substantial proportion with only DCIS (34%), patients who were white (odds ratio [OR], 5.88; 95% confidence interval [95% CI], 3.39-10.19) and had greater state anxiety (OR, 1.04; 95% CI, 1.02-1.07) were more likely to report a higher risk of recurrence, while patients who received radiotherapy (OR, 0.72; 95% CI, 0.54-0.96) and had more social support (OR, 0.59; 95% CI, 0.46-0.75) were less likely to report a higher risk of recurrence. Cancer stage was not significantly associated with perceived risk of recurrence and perceived risk of recurrence did not change significantly over time.

In the only published study with a premorbid assessment of health-related quality of life (HRQoL), Nekhlyudov et al compared changes among women who developed DCIS compared with those who did not in 2 Nurses’ Health Study cohorts using the Medical Outcomes Study 36-Item Short-Form Health Survey. Women who were diagnosed with DCIS had small, but statistically significantly greater, declines in the domains of role limitations due to physical problems, vitality, and social functioning than women without DCIS. Among those with DCIS, clinically significant declines were more often observed within 6 months of the diagnosis in the domains of social functioning and mental health than after 6 months from diagnosis. These data are consistent with other studies that suggest that despite increased anxiety and inaccurate risk perceptions among many women with DCIS, the effects of the diagnosis and treatment on overall HRQoL appear to be limited.

Inaccurate, heightened perceptions of breast cancer risks among women with DCIS have been associated repeatedly with increased anxiety. It is not clear from the current literature whether women with high baseline anxiety are more likely to perceive their risks inaccurately upon the diagnosis of DCIS or whether inaccurate risk perceptions are driving up anxiety levels. Regardless, it is likely that any intervention to improve risk perceptions will need to address not only understanding and informational gaps, but address and manage anxiety as well.
Decision-Making in DCIS

Inaccurate risk perceptions and anxiety about DCIS may hamper optimal, high-quality, shared decision-making. Patient-centered care entails shared decision-making between patients and providers and requires that the patient is engaged and accurately informed about options and outcomes so that treatment decisions can be consistent with the patient’s goals, preferences, and values (Fig. 2).\textsuperscript{38-52} Patient-centered care not only incorporates the patient’s (and, potentially, loved ones’) perspective into the care planning and delivery, but aims to provide ongoing support to meet patient needs (medical and psychosocial) as best as possible and implies responsiveness to those needs. This requires patient-centered communication, which includes fostering healing relationships with providers in which trust is key, accurate information exchange regarding the implications of disease and potential risks and benefits of treatments, provider response to emotions, and assistance with decision-making and managing uncertainty as well as enabling self-management.\textsuperscript{53} Providing this optimal care in our complex health care environment for every patient poses challenges and research has suggested that substantial gaps exist.\textsuperscript{50} In cancer survivors, there is evidence that physicians who adopt a participatory decision-making style are likely to facilitate patient empowerment and enhance the patient’s HRQoL.\textsuperscript{54}

Optimizing patient-centered care may be particularly valuable when caring for patients with DCIS in whom there is such confusion regarding the diagnosis as well as uncertainty in available knowledge about the disease. Interventions directed toward improving communication styles among physicians who care for women with DCIS may lead to more accurate risk perceptions, more informed decision-making, and better psychosocial outcomes in this population, although this has not been studied prospectively. Among women with DCIS, large cross-sectional, population-based studies have revealed that many women do not perceive that they were offered a choice between surgical treatment options.\textsuperscript{29,32} Not surprisingly, surgeon recommendations, which appear to take into account important clinical factors, heavily influence treatment decisions. Patient attitudes also appear to play an important role in treatment decisions. Knowledge about differences in clinical benefits and risks between surgery options has been found to be low among patients and satisfaction with the decision-making process significantly lower in women who did not perceive a choice between surgery options.\textsuperscript{29}

There is also some evidence that attention to distress, as well as informational needs, in women with DCIS may improve psychosocial outcomes. A small cross-sectional interview study of a multiethnic group of women with DCIS revealed ethnic differences in cognitive and emotional responses to DCIS.\textsuperscript{55} White women generally reported a better understanding of their diagnosis and treatment, and Latinas generally reported more distress. Regardless of ethnicity, the women preferred that physicians discuss DCIS treatment options and attend to their informational and emotional needs. Furthermore, satisfaction was associated with adequate information, expediency of care, and the physician’s sensitivity to the patient’s emotional needs.

Patient decision aids may help to improve risk communication, decision-making, and distress for women with DCIS. They have been shown to be feasible and acceptable;
increase patient involvement; and are more likely to lead to informed, values-based health-related decisions.56 They also help patients to make health decisions and reduce decisional conflict. Furthermore, decisions made with the use of decision aids are more likely to be based on better knowledge, more realistic expectations, clearer values, and better communication. They have been studied among women with invasive breast cancer and found to improve communication and knowledge, reduce decisional conflict, and enable women to make a choice regarding surgical treatments.57,58 No published studies of a decision aid have focused on women with DCIS, although there are available decision aids in use currently focused on treatment decisions for women with DCIS (available at: http://decisionaid.ohri.ca/Azsumm.php?ID=1187 [accessed January 5, 2012]).

There is clearly a need to identify the mediators and moderators of the link between communication and patient outcomes in women with DCIS. Future research is warranted to understand and intervene in the complex relationship between risk perceptions, anxiety/distress, and decision-making. Decision aids are important tools to facilitate ongoing patient-clinician communication (not replace it) and further research on how decision aids affect communications, decision-making, knowledge, and risk perceptions as well as psychosocial outcomes among women with DCIS should be conducted.

Nomenclature Issues: What’s in a Name?

There has been discussion over the past few decades about modifying the nomenclature of DCIS to remove the term “carcinoma.” In particular, proponents of this approach have recommended replacing DCIS with “ductal intraepithelial neoplasia” or “DIN” terminology.59–61 A new clinical and biological TNM classification for breast cancer currently being used in Italy has renamed DCIS as “DIN, ductal intraepithelial neoplasia.”61–63 Proponents of this approach note that the term “intraepithelial neoplasia” would be consistent with the terminology currently used for precursor lesions in other organs such as the cervix, vulva, prostate, and pancreas. It has also been argued that a name change to “DIN” would improve interobserver agreement in the diagnosis of preinvasive breast lesions and would eliminate the need to make the subjective distinction between atypical ductal hyperplasia and low-grade DCIS. At this time, however, there are no data to indicate that changing the nomenclature would improve observer reproducibility.60

It has also been suggested that removing “carcinoma” from the terminology for a disease that should not be able to spread to other parts of the body and threaten a woman’s life could lead to decreased anxiety among patients, improve risk perceptions, and help in decision-making.8 However, there are no data at this point to suggest that a name change will have an effect on risk perceptions, anxiety/distress, or decision-making.

Concern has been raised that the heterogeneity of DCIS, the use of treatment options that are similar to those used for patients with invasive breast cancer, and the limited ability to stratify risk using available clinical and pathologic parameters would limit the potential for a name change to improve risk perceptions and reduce anxiety. In addition, a change in terminology would not result in a change in the treatment options for patients with this disease and might lead to more confusion rather than less for patients and providers, particularly those providers at the periphery of the care of patients with breast cancer. The traditional terminology is well established and deeply embedded with an associated extensive scientific literature. There are few citations from a limited number of authors considering the proposed DIN terminology. Some patient advocates have also expressed concern that changing the name could be construed by women as duplicitous and patronizing, and patients may ultimately experience similar distress to the term “neoplasia” in the DIN terminology compared with the term “carcinoma” in DCIS. It has been noted that the term “lobular carcinoma in situ” does not appear to generate the same anxiety or concerns as DCIS, possibly because the treatment recommendations for women with DCIS are much more aggressive, a fact that would not change with a name change. Some advocates have suggested that research on biology, such as predictive and prognostic markers for DCIS that might help guide treatment decisions, and research to improve communication is a better use of resources than implementing a new nomenclature.

However, proponents suggest that a name change could be feasible if it were done in a phased approach: 1) first, discussions regarding terminology introduced in interdisciplinary settings; 2) next, pathology reports transitioning to include the traditional terminology along with the DIN equivalent in parentheses; 3) subsequently, the DIN designation being placed first on the pathology report followed by the traditional DCIS terminology in parentheses; and 4) finally, only the DIN terminology being used on pathology reports.60

In 2011, the World Health Organization Working Group for classification of tumors of the breast noted that the DIN terminology has not gained widespread acceptance, in part because no new diagnostic criteria are used, and suggested that a change in terminology would therefore not help with improving interobserver reproducibility.15 In light of ongoing and future work in this area, the Working Group recommended that the “classification of
intraductal proliferative lesions should be viewed as an evolving concept that may be modified as additional molecular and genetic data become available. 15

In summary, while a change in terminology may be worthy of consideration in the future, there are no data to support the contention that a name change at the present time will reduce observer variability in diagnosis, alleviate patient anxiety, or assist patients and clinicians in choosing among the various treatment options for DCIS, which will be the same regardless of the terminology used. Furthermore, a name change should not be viewed as a substitute for communicating what DCIS means in terms of prognosis and treatment options. Many believe that clinical usefulness and patient benefit should drive the efforts for changing DCIS nomenclature and that at this time, efforts should be focused on ensuring that pathologists provide as accurate and consistent reporting of DCIS cases as possible.

Conclusions and Future Directions

The accuracy of perceived risk, anxiety, and decision-making among women with DCIS would likely be improved by better patient-clinician communication about the disease, the enhanced provision of psychosocial support, and better recognition and treatment of coexisting anxiety. 33,44 However, until we have a better understanding of the disease and predictors of risk and biologic behavior and are able to develop more tailored therapy for individuals, the high level of uncertainty about the disease will continue to pose substantial challenges to informed decision-making and psychosocial outcomes. 51 Nevertheless, to improve the situation, decisions aids are important tools to facilitate ongoing patient-clinician communication (not replace it), and further research among women with DCIS is clearly warranted. Careful attention to shared decision-making and eliciting and considering a woman’s preferences when helping her to make treatment decisions, as well as screening for and addressing anxiety in such patients, can improve the care of individual patients.

Continued increases in DCIS diagnoses due to imaging advances and an aging population mandate improved communication about DCIS among professionals involved in the diagnosis and treatment of patients with the disease. Research is needed to understand better the biology and mechanisms of the progression of DCIS to invasive breast cancer and the factors that predict those subtypes of DCIS that do not progress, and to improve communication between patients and providers. There was no consensus among attendees at the workshop to support changing the nomenclature of DCIS. In the future, we seek to 1) evaluate the process by which nomenclature changes were made in other diseases and determine the extent to which communication influenced implementation and the QoL of the patients, and 2) obtain information from other countries (including Italy) where recent nomenclature changes have been adopted regarding the resulting effects of the changes on risk perceptions, psycho-social outcomes, and decision-making.

References

1. Proceedings of the National Institutes of Health State-of-the-Science Conference, Diagnosis and Management of Ductal Carcinoma In Situ, September 2009. J Natl Cancer Inst Monogr. 2010;2010(41):111-222.
2. Allegra CJ, Aberle DR, Ganschow P, et al. National Institutes of Health State-of-the-Science Conference statement: Diagnosis and Management of Ductal Carcinoma In Situ September 22-24, 2009. J Natl Cancer Inst. 2010;102:161-169.
3. McCaskill-Stevens W. National Institutes of Health State-of-the-Science Conference on the Management and Diagnosis of Ductal Carcinoma in Situ: a call to action. J Natl Cancer Inst Monogr. 2010;2010(41):111-112.
4. Graff S. Ductal carcinoma in situ: should the name be changed? J Natl Cancer Inst. 2010;102:6-8.
5. StatBite: relative survival and incidence rates: ductal carcinoma in situ. J Natl Cancer Inst. 2010;102:8.
6. Kerlikowske K. Epidemiology of ductal carcinoma in situ. J Natl Cancr Inst Monogr. 2010;2010(41):139-141.
7. DeSantis C, Siegel R, Bandi P, Jemal A. Breast cancer statistics, 2011. CA Cancer J Clin. 2011;61:409-418.
8. Leonard GD, Swain SM. Ductal carcinoma in situ, complexities and challenges. J Natl Cancer Inst. 2004;96:906-920.
9. Allred DC. Biomarkers predicting recurrence and progression of ductal carcinoma in situ treated by lumpectomy alone. J Natl Cancer Inst. 2010;102:585-587.
10. Bijker N, van Tienhoven G. Local and systemic outcomes in DCIS based on tumor and patient characteristics: the radiation oncologist’s perspective. J Natl Cancer Inst Monogr. 2010;2010(41):178-180.
11. Schnitt SJ. Local outcomes in ductal carcinoma in situ based on patient and tumor characteristics. J Natl Cancer Inst Monogr. 2010;2010(41):158-161.
12. Sanders ME, Schuyler PA, Dupont WD, Page DL. The natural history of low-grade ductal carcinoma in situ of the breast in women treated by biopsy only revealed over 30 years of long-term follow-up. Cancer. 2005;103:2481-2484.
13. Burstein HJ, Polvak K, Wong JS, Lester SC, Kaelin CM. Ductal carcinoma in situ of the breast. N Engl J Med. 2004;350:1430-1441.
14. Solin LJ, Gray R, Baehner FL, et al. A quantitative multigene RT-PCR assay for predicting recurrence risk after surgical excision alone without irradiation for ductal carcinoma in situ (DCIS): a prospective validation study of the DCIS score from ECOG ES194. Cancer Res. 2011;71(suppl 24):1086.
15. Lakhan SR, Ellis IO, Schnitt SJ, Tan PH, Van de Vijver MJ, eds. WHO Classification of Tumours of the Breast. Lyon: IARC Press. In press.
16. Kerlikowske K, Molinario AM, Gauthier ML, et al. Biomarker expression and risk of subsequent tumors after initial ductal carcinoma in situ diagnosis. J Natl Cancer Inst. 2010;102:627-637.
17. Fong J, Kurniawan ED, Rose AK, et al. Outcomes of screening-detected ductal carcinoma in situ treated with wide excision alone. Ann Surg Oncol. 2011;18:3778-3784.
18. Schwartz LM, Woloshin S, Sox HC, Fischhoff B, Welch HG. US women’s attitudes to false positive mammography results and detection of ductal carcinoma in situ: cross sectional survey. BMJ. 2000;320:1635-1640.
19. Webb C, Koch T. Women’s experiences of non-invasive breast cancer: literature review and study report. J Adv Nurs. 1997;25:514-525.
20. Godby CJ. Women’s attitudes to false positive mammography results. A formerly clueless patient responds. BMJ. 2000;321:1409-1410; discussion 1410-1411.
21. De Morgan S, Redman S, White KJ, Cakir B, Boyages J. “Well, have I got cancer or haven’t I?” The psycho-social issues for women diagnosed with ductal carcinoma in situ. Health Expect. 2002;5:310-318.
22. Prinjha S, Evans J, McPherson A. Women’s information needs about ductal carcinoma in situ before mammographic screening and after diagnosis: a qualitative study. J Med Screen. 2006;13:110-114.
23. De Morgan S, Redman S, D’Este C, Rogers K. Knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma in situ (DCIS). Patient Educ Couns. 2011;84:62-68.
24. Davey C, White V, Warne C, Kitchen P, Vil-lanueva E, Erbas B. Understanding a ductal carcinoma in situ diagnosis: patient views and surgeon descriptions. Eur J Cancer Care (Engl). 2011;20:776-784.
25. Carrera C, Payne S. Ductal carcinoma in situ (DCIS) of the breast: the need for psychosocial research. Psychooncology. 1999;8:538-545.
26. Kennedy F, Harcourt D, Rumsey N. The challenge of being diagnosed and treated for ductal carcinoma in situ (DCIS). Eur J Oncol Nurs. 2008;12:103-111.
27. Edge SB, Byrd DR, Compton CC, Fritz AG, Greene FL, Trotti A, eds. AJCC Cancer Staging Manual. New York: Springer; 2010:646.
28. Partridge A, Winer JP, Golshan M, et al. Perceptions and management approaches of physicians who care for women with ductal carcinoma in situ. Clin Breast Cancer. 2008;8:275-280.
29. Katz SJ, Lantz PM, Zemencuk JK. Correlates of surgical treatment type for women with noninvasive and invasive breast can-
cer. J Womens Health Gend Based Med. 2001;10:659-670.
30. Ceilley E, Jagsi R, Goldberg S, et al. Patterns and correlates of local therapy for women with ductal carcinoma-in-situ. J Clin Oncol. 2005;23:3001-3007.
31. Yen TW, Kueer HM, Ottesen RA, et al. Impact of randomized clinical trial results in the national comprehensive cancer network on the use of tamoxifen after breast surgery for ductal carcinoma in situ. J Clin Oncol. 2007;25:3251-3258.
32. Kennedy F, Harcourt D, Rumsey N. White P. The psychosocial impact of ductal carcinoma in situ (DCIS): a longitudinal study of factors associated with perceived risk of recurrence in women with ductal carcinoma in situ and early-stage invasive breast cancer. Breast Cancer Res Treat. 2010;124:835-844.
33. Liu Y, Perez M, Aft RL, et al. Accuracy of perceived risk of recurrence among patients with early-stage breast cancer. Cancer Epidemiol Biomarkers Prev. 2010;19:675-680.
34. Liu Y, Perez M, Schootman M, et al. Longi-
gitudinal study of factors associated with perceived risk of recurrence in women with ductal carcinoma in situ and early-stage invasive breast cancer. Breast Cancer Res Treat. 2010;124:835-844.
35. Kennedy F, Harcourt D, Rumsey N. White P. Impact of randomized clinical trial results in the national comprehensive cancer network on the use of tamoxifen after breast surgery for ductal carcinoma in situ. J Clin Oncol. 2007;25:3251-3258.
36. Kaplan CP, Napoles AM, Hwang ES, et al. Selection of treatment among Latina and non-Latina white women with ductal carci-
noma in situ. J Womens Health (Larchmt). 2011;20:213-223.
37. Amichetti M, Caffo O, Arcicasa M, et al. Qual-
ity of life in patients with ductal carcinoma in situ of the breast treated with conservative surgery and postoperative irradiation. Breast Cancer Res Treat. 1999;54:109-115.
38. Nekhlyudov L, Kroeneh CH, Jung I, Holmes MD, Colditz GA. Prospective changes in quality of life after ductal carcinoma-in-situ: results from the Nurses’ Health Study. J Clin Oncol. 2006;24:2822-2827.
39. Partridge A, Adloff K, Blood E, et al. Risk perceptions and psychosocial outcomes of women with ductal carcinoma in situ: longitudinal results from a cohort study. J Natl Cancer Inst. 2008;100:243-251.
40. Kaplan CP, Napoles AM, Hwang ES, et al. Impact of randomized clinical trial results in the national comprehensive cancer network on the use of tamoxifen after breast surgery for ductal carcinoma in situ and early-stage invasive breast cancer. Breast Cancer Res Treat. 2010;124:835-844.
41. Bluman LG, Borstelmann NA, Rimer BK, Iglehart JD, Winer EP. Knowledge, satisfac-
tion, and perceived cancer risk among women diagnosed with ductal carcinoma in situ. J Womens Health Gend Based Med. 2001;10:589-598.
42. van Gestel YR, Voogd AC, Vingerhoets AJ, et al. A comparison of quality of life, disease impact and risk perception in women with invasive breast cancer and ductal carci-
noma in situ. Eur J Cancer. 2007;43:549-556.
43. Liu Y, Perez M, Aft RL, et al. Accuracy of perceived risk of recurrence among patients with early-stage breast cancer. Cancer Epidemiol Biomarkers Prev. 2010;19:675-680.
44. Liu Y, Perez M, Schootman M, et al. A longi-
gitudinal study of factors associated with perceived risk of recurrence in women with ductal carcinoma in situ and early-stage invasive breast cancer. Breast Cancer Res Treat. 2010;124:835-844.
45. Kennedy F, Harcourt D, Rumsey N. White P. The psychosocial impact of ductal carcinoma in situ (DCIS): a longitudinal study of factors associated with perceived risk of recurrence in women with ductal carcinoma in situ and early-stage invasive breast cancer. Breast Cancer Res Treat. 2010;124:835-844.
46. Liu Y, Perez M, Schootman M, Aft RL, Gil-
landers WE, Jeffe DB. Correlates of fear of cancer recurrence in women with ductal carcinoma in situ and early invasive breast cancer. Breast Cancer Res Treat. 2011;130:165-173.
47. Rudd K, Meyer M, Giobbiiee-Hurder A, et al. Long-Term Risk Perceptions and Quality of Life of Women with Ductal Carcinoma In Situ. Cancer Res. 2010. Abstract P3-15-01.
48. Charles C, Gafni A, Whelan T. Shared deci-
sion-making in the medical encounter: what does it mean? (or it takes at least two tango). Soc Sci Med. 1997;44:681-692.
49. Mulley AG Jr. Assessing patients’ utilities. Can the ends justify the means? Health Aff (Millwood). 2003;22:9-34.
50. Epstein RM, Street RL. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. Bethesda, MD: National Cancer Institute; 2007.
51. Elmore JG, Ganschow PS, Geller BM. Communication between patients and providers and informed decision making. J Natl Can-
cer Inst Monogr. 2010;2010(41):204-209.
52. Fowler FJ Jr, Levin CA, Sepucha KR. Informing and involving patients to improve the quality of medical decisions. Health Aff (Millwood). 2011;30:699-706.
53. Arora NK, Street RL Jr, Epstein RM, Butow P. Facilitating patient-centered cancer communication: a road map. Patient Educ Couns. 2009;77:319-321.
54. Arora NK, Weaver KE, Clayton ML, Oakley-
Girvan I, Potosky AL. Physicians’ decision-making style and psychosocial outcomes among cancer survivors. Patient Educ Couns. 2009;77:404-412.
55. de Vogel van der CR. Jagsi R, Goldberg S, et al. Decision aids for people facing health treat-
ment or screening decisions. Cochrane Database Syst Rev. 2009(3):CD001431.
56. Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer sur-
gery: a randomized trial. JAMA. 2004;292:435-441.
57. Collins ED, Moore CP, Clay KC, et al. Can women with early-stage breast cancer make an informed decision for mastec-
tomy? J Clin Oncol. 2009;27:519-525.
58. Pavuluri FA. Ductal carcinoma in situ: intro-
duction of the concept of ductal intraepi-
thelial neoplasia. Mod Pathol. 1998;11:140-154.
59. Pavuluri FA. Breast pathology: rationale for adopting the ductal intraepithelial neoplasia (DIN) classification. Nat Clin Pract Breast. 2009;5:116-117.
60. Pavuluri FA. Breast pathology: rationale for adopting the ductal intraepithelial neoplasia (DIN) classification. Nat Clin Pract Breast. 2009;5:116-117.
61. Veronesi U, Viale G, Rotmensz N, Gold-
hirsch A, Rethinking TNM: breast cancer TNM classification for treatment decision-making and research. Breast. 2006;15:3-8.
62. Veronesi U, Zurrada S, Goldhirsch A, Rot-
mensz N, Viale G. Breast cancer classifica-
tion: time for a change. J Clin Oncol. 2009; 27:2427-2428.
63. Veronesi U, Zurrada S, Viale G, Calimberti V, Arnone P, Nole F. Rethinking TNM: a breast cancer classification to guide to treat-
ment and facilitate research. Breast J. 2009; 15:291-295.