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DCIS biology, language, and active surveillance: A survey of breast radiologists' knowledge and opinions

Lars J Grimm,

Duke University Medical Center, Department of Radiology – Box 3808, Durham, NC 27710

Stamatia Destounis,

University of Rochester Medical Center, 126 Court St, Geneseo, NY 14454

Habib Rahbar,

University of Washington, University of Washington School of Medicine, Department of Radiology, Seattle Cancer Care Alliance, 1144 Eastlake Ave East, LG2-211, Seattle, WA 98109

Mary Scott Soo, MD,

Duke University Medical Center, Department of Radiology – Box 3808, Durham, NC 27710

Steven P Poplack

Mallinckrodt Institute of Radiology, Washington University School of Medicine in St. Louis, 4921 Parkview Place, Saint Louis, MO 63110

Abstract

Purpose: To understand how breast radiologists perceive ductal carcinoma in situ (DCIS).

Materials and methods: A 19-item survey was developed by the Society of Breast Imaging Patient Care and Delivery Committee and distributed to all SBI members. The survey queried respondents' demographics, knowledge of DCIS biology, language used to discuss a new diagnosis of DCIS, and perspectives on active surveillance for DCIS. Five-point Likert scales (1=strongly disagree, 3=neutral, 5=strongly agree) were used.

Results: There were 536 responses for a response rate of 41%. There was agreement that DCIS is the primary driver of overdiagnosis in breast cancer screening (median 4) and respondents provided mean and median overdiagnosis estimates of 29.7% and 25% for low-grade DCIS as well as 4.2% and 0% for high-grade DCIS respectively. Respondents were varied in how they describe DCIS but most often use the word 'cancer' with a qualifier such as early (32%) or pre-invasive (25%). Respondents disagreed (median 2) with removing the word 'carcinoma' from DCIS. Finally, there was agreement that current standard of care therapy for some forms of DCIS is overtreatment (median 4) and that active surveillance as an alternative management strategy should be studied (mean 4), but felt that US (median 4) and MRI (median 4) should be used to exclude women with occult invasive disease prior to active surveillance.

Corresponding Author: Lars J Grimm, Phone: (919) 684-7293, Fax: (919) 684-7151, lars.grimm@duke.edu.

All authors participated in the study design, data analysis, and writing/editing of the manuscript.

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Conclusions: Breast radiologists' opinions about DCIS biology, language, and active surveillance are not homogenous but general trends exist which can be used to guide research, education, and advocacy efforts.

Keywords

DCIS; survey; active surveillance; overdiagnosis; overtreatment; breast imaging

Introduction

Ductal carcinoma in situ (DCIS) is a non-invasive stage 0 form of breast cancer that has steadily increased in incidence since the widespread adoption of screening mammography and now represents approximately one third of new breast cancer diagnoses in the United States.(1, 2) DCIS alone has no metastatic potential but since some DCIS lesions may progress to invasive disease, it is standard of care to offer surgery with or without radiation therapy for all newly diagnosed DCIS.(3, 4) As a result, the natural history of DCIS is largely unknown. However, there is a general acknowledgement that some DCIS lesions are overdiagnosed resulting in overtreatment especially for older women with competing mortality risks or in cases of low-grade DCIS which are thought to be less biologically aggressive. As a result, the growing concerns regarding breast cancer screening and overdiagnosis which have helped to drive conflicting breast cancer screening guidelines may be predominately influenced by DCIS and not invasive cancer.(5) This has prompted new approaches to the discussion and treatment of DCIS.

In an attempt to help reduce DCIS overtreatment, active surveillance is a management strategy that avoids standard of care surgical excision in favor of close monitoring. Limited data suggests low-risk forms of DCIS have comparable survival benefits between surgical and non-surgical treatments.(6) There are currently three prospective active surveillance trials in progress to formally test the safety and feasibility of active surveillance for DCIS. (7–9) Coinciding with efforts to change the management of DCIS are efforts to rename DCIS to ductal intraepithelial neoplasia (DIN) or indolent lesion of epithelial origin (IDLE). (10–12) Intraepithelial neoplasias of the cervix, vagina, and vulva have subsequently been renamed to remove the word carcinoma and advocates for renaming DCIS argue that this will make patients and providers more willing to accept alternative management strategies. Changes to the nomenclature and management of DCIS have to date been primarily driven by the medical and surgical communities, and it is unclear if these efforts have gained a foothold among breast radiologists.

The diagnosis and management of DCIS involves radiologists, surgeons, medical oncologists, and radiation oncologists, all of whom can influence the way a patient thinks and responds to a new diagnosis of DCIS. Therefore, the purpose of this study is to understand how breast radiologists think and talk about DCIS, specifically with a focus on biology, language, and active surveillance. A more complete understanding of the breast radiologists' perspective can thus be used to guide educational, outreach, and research endeavors.

Materials and Methods

Survey development

A 19-item survey was developed by the Society of Breast Imaging (SBI) Patient Care and Delivery Committee to understand how breast radiologists perceive DCIS. Demographic information including age, gender, years since training, breast imaging training, proportion of clinical practice in breast imaging, and current practice environment was collected. The survey was divided into three sections: DCIS biology, DCIS language, and active surveillance. The DCIS biology section addressed issues of overdiagnosis and overtreatment and asked respondents to give percentage estimates of overdiagnosis for low and high nuclear grade DCIS. The DCIS language section asked about specific word choice used by radiologists when conveying a new diagnosis of DCIS and whether that discussion is tailored based on DCIS biology. Finally, the active surveillance section queried familiarity and perspectives regarding active surveillance as a management strategy. Prior to questions on overdiagnosis, overtreatment, and active surveillance, formal definitions of these terms were provided to ensure a baseline level of understanding.

The survey instrument was initially developed by a core group of three breast radiologists before being shared with a larger group of approximately 15 breast radiologists who represent the target study population. Iterative feedback was generated and refinements to the organization, language, and content structure of the survey were made throughout the initial development and pre-release testing. The final version of the administered survey is shown in Appendix 1.

Survey administration and response rate

The survey was sent electronically to SBI members via email on October 13, 2019 from the SBI Patient Care and Delivery Committee. Two reminder emails were sent and a reminder announcement was made at the SBI gathering at RSNA 2019. The survey email contained an electronic link to the survey hosted on Survey Monkey (San Mateo, CA). The survey was open for data collection for seven weeks. The email was received and opened by 1,318 recipients and there were 536 participants who completed at least some component of the survey for a response rate of 41%.

Data analysis

Comparisons were made between survey responses and the demographic variables using Chi-squared and independent t-tests as appropriate. Median scores were calculated for all Likert responses. A median score of 1 or 2 indicated disagreement with the proposed statement, a median score of 3 indicated neither agreement nor disagreement (i.e., neutral), and a median score of 4 or 5 indicated agreement with the proposed statement. Likert scores were coded as ordinal variables and left as a five-point scale for subsequent multivariate analysis which was performed with the demographic variables as inputs. Inter-rater agreement statistics were calculated for select questions expected to hang together. Statistical analysis was performed using JMP Pro (version 15.0.0, SAS Institute, Cary, NC).

Results

Demographics

Respondent demographic information is shown in Table 1. The average respondent was 49.6 ± 10.9 years old. The majority of respondents were female (73%), have been in practice greater than 10 years (20% for 11–20 years and 39% for >20 years), were trained as breast imaging fellows (66%), spend greater than 75% of their clinical time on breast imaging (72%), and are in private practice (53%).

DCIS biology

On a five-point Likert scale (1=strongly disagree, 3=neutral, 5=strongly agree), when respondents were asked to consider the statement, “The overdiagnosis attributed to breast cancer screen is primarily the result of DCIS,” the median response was 4 indicating agreement (Figure 1). No demographic factors were significantly associated with these estimates. When respondents were asked to consider the statement, “Some forms of DCIS are overtreated with current standard of care treatment regimens,” the median response was 4 indicating agreement (Table 2). On the ordinal logistic regression model, only years in practice was associated with the response ($p=0.04$) with more experienced respondents indicating greater agreement. Sixty-two-point-six percent of respondents with greater than 20 years of experience indicated strong agreement or agreement, compared to 54.7%, 46.6%, and 45.4% of respondents with less than 5 years, 5–10 years, and 11–20 years respectively. The mean and median estimate of overdiagnosis for low-grade DCIS was 29.7% (standard deviation [SD]: 24.3%) and 25% (interquartile range [IQR]: 40%) respectively. There were no demographic factors associated with these estimates. The mean and median estimate of overdiagnosis for high-grade DCIS were 4.2% (SD: 10.5%) and 0% (IQR: 5%). Respondents in a hybrid private/academic practice provided mean estimates (6.6%, SD: 15.6%) approximately double that of academic (3.3%, SD: 8.4%) and private practice (3.7%, SD: 9.1%) respondents ($p=0.04$). The inter-rater agreement for these two questions demonstrated a Kappa of 0.25.

DCIS language

When respondents were asked, “When sharing with a patient she has a new diagnosis of DCIS, what word or phrase best describes how you refer to DCIS?” the most common responses were “early cancer” ($n=156$, 32%), “pre-invasive cancer” ($n=123$, 25%), and “cancer cells in the duct” ($n=111$, 23%) as shown in Figure 1. On the five-point Likert scale, respondents disagreed (median 2) with the statement, “DCIS should be renamed to a new name that does not include the word ‘carcinoma’,” as shown in Table 3. On the ordinal logistic model greater disagreement was found for women (68.5% vs 52.9% for men, $p=0.001$), those in an academic practice environment (68.7% vs 56.8% for hybrid practice and 54.2% for private practice, $p=0.006$), and those with breast fellowship training (68.4% vs 57.1% for no fellowship training and 56.2% for training prior to fellowships, $p=0.04$) were more likely to disagree with renaming DCIS. There was no consensus (mean 3) when respondents were asked, “When sharing with a patient she has a new diagnosis of DCIS, how likely are you to change your discussion based on the ER, PR, and/or nuclear grade?” with no differences by demographics.

Active surveillance

Respondents were asked five questions on a five-point Likert scale. Respondents agreed (median 4) with the statement, “I am familiar with the general concepts of active surveillance for DCIS?” as shown in Table 4. On the ordinal logistic model, respondents in an academic practice environment ($p<0.001$), who were older ($p=0.01$), and with a greater percentage of breast in clinical practice ($p=0.01$) were more likely to agree. When respondents were asked, “I am familiar with the DCIS active surveillance trials that are currently in progress?,” the median response was 3 indicating no consensus. On the ordinal logistic model, stronger agreement was significantly associated with a greater percentage of breast in clinical practice (67.6% for those who practice 75%–100% breast imaging vs 51.2% for those who practice 50%–75% and 48.7% for those who practice 25%–50% and 33.2% for those who practice less than 25%, $p<0.001$), older age ($p=0.004$), and an academic practice environment (78.4% vs 59.7% for hybrid practices and 55.4% for private practices, $p=0.01$). Respondents also agreed (median 4) when asked, “It is important to study active surveillance as an alternative management strategy for select women with low-risk DCIS?,” but no demographic factors influenced these responses. Inter-rated agreement for familiarity with active surveillance general concepts and clinical trials demonstrated a Kappa of 0.39.

Respondents were also told that “DCIS most commonly presents as calcifications on mammography,” and asked if supplemental ultrasound and MRI were important to exclude occult invasive disease. There was agreement for using both ultrasound (median 4) and MRI (median 4). On the ordinal logistic models, training prior to the existence of breast imaging fellowship indicated stronger agreement with using MRI (73.0% vs 57.4% for fellowship training and 49.0% for no fellowship training, $p=0.009$). The inter-rated agreement for use of MRI and US questions demonstrated a Kappa of 0.11.

Discussion

Overdiagnosis discussions influence health policy decision making regarding breast cancer screening guidelines. Our study provides insights into how breast radiologists approach DCIS, specifically with regards to DCIS biology, language, and active surveillance. Respondents agreed that DCIS is the primary driver of overdiagnosis in breast cancer screening, but their overdiagnosis estimates for low- (mean: 29.7% and median: 35%) and high-grade (mean: 4.2% and median: 0%) DCIS are much lower than estimates in the literature (20%–91%).(13–25) Almost all published DCIS overdiagnosis estimates are based on modeling studies which vary depending on available data, modeling assumptions, model structures, and biological assumptions. Furthermore, only one published modeling study provides estimates by nuclear grade: 61% for low-, 57% for intermediate- and 45% for high-nuclear grade DCIS.(23) Breaking down overdiagnosis rates by nuclear grade is important as active surveillance trial eligibility is based on nuclear grade. The true natural history of DCIS is unknown and performing a new randomized controlled trial of screened and unscreened women until death to actually measure overdiagnosis rates would be unethical. (5, 24) The only published study that included data from actual randomized controlled trials (the Swedish Two-County Trial and the Gothenburg Trial) demonstrated an upper limit of

DCIS overdiagnosis as 15%, which falls well within the estimates of respondents in this study.(25) The results of our study demonstrate a large gap between the opinions of radiologists and the modeling community on DCIS overdiagnosis.

The responses to DCIS language demonstrated some consensus and an aversion to change. As expected, there was no universal agreement regarding the specific word choice used to describe DCIS, but the overwhelming majority of respondents use the word ‘cancer’ with some added qualifier: early (32%), pre-invasive (25%), cells in the duct (23%), or stage 0 (10%). Reinforcing the practice of using the word ‘cancer’ to describe DCIS, respondents were also not in favor of renaming DCIS to remove the word ‘carcinoma’ with 37% of respondents indicating strong disagreement. Interestingly, stronger disagreement was felt among women, those in an academic environment, and those with fellowship training, which suggests an unwillingness to deemphasize the potential risks of DCIS among those in academics or with more formal training. Since breast biopsy results are frequently first shared by radiologists, any changes to the nomenclature of DCIS will likely need support from breast imaging radiologists, which currently appears limited. Finally, there was no consensus on whether information related to ER, PR, and nuclear grade influence discussions with patients. We hypothesize that this is likely because ER and PR status are not typically available at the time of initial diagnosis and additional testing on the larger surgical excision specimens might change these biological variables, so respondents are not incorporating this information into discussions.

Respondents agreed that some forms of DCIS are currently overtreated and were in favor of studying active surveillance as an alternative management strategy. Respondents in an academic environment and who practice a greater share of breast imaging were more familiar with the general concepts of active surveillance which demonstrates the need for outreach efforts to educate members of the broader breast imaging community. Similarly, there was greater familiarity regarding the active surveillance trials among academic radiologists and those who practice predominately breast imaging. There is currently only one active surveillance trial enrolling patients in the United States, the Comparison of Operative to Monitoring and Endocrine Therapy trial for Low Risk DCIS (COMET), which to date has enrolled less than 250 patients, so it is not surprising that radiologists would not be familiar with the trial details.(7) Most interestingly though was the agreement that both supplemental US and MRI should be used to exclude occult invasive disease in active surveillance eligible patients. The safe use of active surveillance depends in large part on the ability to identify patients with pure DCIS, but previous efforts to predict occult invasive disease on mammography have shown limited success (26–28). Respondents may feel that the added information provided by multi-modality imaging will give them more confidence in excluding invasive disease. Currently, the active surveillance trials in progress do not require US or MRI for enrollment, but supplemental imaging is allowed at the discretion of the primary treatment team.(7–9) The added value of US and MRI to detect occult invasive disease in active surveillance-eligible patients has not been fully explored but likely warrants additional investigation.

There are limitations to our study. All surveys are at risk of response bias, but the survey was anonymous to minimize this influence. There is the risk of misinterpreting questions and

particularly some of the terms used, such as overdiagnosis, overtreatment, and active surveillance. This was mitigated by providing formal definitions preceding specific questions to ensure a baseline level of understanding and multiple rounds of question testing and refinement. However, there is no way to ensure that respondents read these definitions. Additionally, the order of answer choices could not be randomized which might have favored response options listed earlier. Finally, the respondents were members of the SBI who are predominately subspecialty trained and practice breast imaging. Thus, these results may not apply to general radiologists who perform breast imaging and interventions less frequently. Furthermore, detailed demographics are not available from the SBI to determine if the respondents are generalizable with the entire SBI membership.

In conclusion, this survey captured some important insights into the perceptions of DCIS held by breast radiologists. Specifically, there is consensus that DCIS is the primary driver of overdiagnosis in breast cancer screening although estimates of overdiagnosis rates are far lower than those reported by modeling studies. Second, respondents use the word cancer to describe DCIS to patients and are not in favor of renaming DCIS to remove ‘carcinoma.’ Finally, active surveillance is viewed as a promising management strategy for some forms of DCIS and there is general familiarity with the concepts, but there is a desire for supplemental imaging to exclude patients with occult invasive disease. These findings can be used to help guide education, outreach, and research endeavors for DCIS. It will be important for breast radiologists to engage in the multi-disciplinary dialog of DCIS given their central role in diagnosis and patient communication.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Responses to the question, “When sharing with a patient she has a new diagnosis of DCIS, what word or phrase best describes how you refer to DCIS?”

Table 1.

Respondent demographic information

Demographic	N (%) or Mean (SD)
All	536 (100)
Age, years	49.6 (10.9)
Missing	13 (2.4)
Gender	
Male	146 (27)
Female	390 (73)
Years in practice	
<5 years	99 (18)
5–10 years	119 (22)
11–20 years	109 (20)
>20 years	209 (39)
Training	
No breast imaging fellowship	59 (11)
Breast imaging fellowship	353 (66)
Trained prior to breast imaging fellowships, but have practiced primarily breast imaging during my career	124 (23)
Percentage of clinical practice dedicated to breast	
0–25%	13 (2)
25–50%	45 (8)
51–75%	92 (17)
76–100%	386 (72)
Current practice environment	
Private practice	287 (53)
Hybrid private practice/academic or community division of academic practice	107 (20)
Academic	142 (26)

Table 2.

Responses to questions related to DCIS biology

Response	N (%)
The overdiagnosis attributed to breast cancer screening is primarily the result of DCIS.	
Strongly agree	125 (26)
Agree	185 (38)
Neutral	77 (16)
Disagree	52 (11)
Strongly disagree	47 (10)
Some forms of DCIS are overtreated with current standard of care treatment regimens.	
Strongly agree	74 (15)
Agree	190 (39)
Neutral	94 (19)
Disagree	79 (16)
Strongly disagree	50 (10)

Table 3.

Responses to questions related to DCIS language

Response	N (%)
DCIS should be renamed to a new name that does not include the word 'carcinoma'.	
Strongly agree	19 (4)
Agree	37 (8)
Neutral	118 (24)
Disagree	132 (27)
Strongly disagree	177 (37)
When sharing with a patient she has a new diagnosis of DCIS, how likely are you to change your discussion based on the ER, PR, and/or nuclear grade?	
Never	88 (18)
Rarely	124 (26)
Occasionally	125 (26)
Often	114 (24)
Always	29 (6)

Table 4.

Responses to questions related to active surveillance

Response	N (%)
I am familiar with the general concepts of active surveillance for DCIS?	
Strongly agree	122 (25)
Agree	178 (37)
Neutral	93 (19)
Disagree	46 (10)
Strongly disagree	41 (9)
I am familiar with the DCIS active surveillance trials that are currently in progress.	
Strongly agree	77 (16)
Agree	151 (31)
Neutral	81 (17)
Disagree	94 (20)
Strongly disagree	77 (16)
It is important to study active surveillance as an alternative management strategy for select women with low-risk DCIS.	
Strongly agree	181 (38)
Agree	174 (36)
Neutral	68 (14)
Disagree	35 (7)
Strongly disagree	21 (4)
It is important to use supplemental ultrasound to exclude occult invasive disease in women considering active surveillance for DCIS.	
Strongly agree	117 (25)
Agree	120 (25)
Neutral	123 (26)
Disagree	68 (14)
Strongly disagree	49 (10)
It is important to use supplemental MRI to exclude occult invasive disease in women considering active surveillance for DCIS.	
Strongly agree	187 (39)
Agree	101 (21)
Neutral	114 (24)
Disagree	58 (12)
Strongly disagree	18 (4)