Addressing overtreatment of ductal carcinoma in situ (DCIS): a qualitative study of how terminology affects women's concern and treatment preferences

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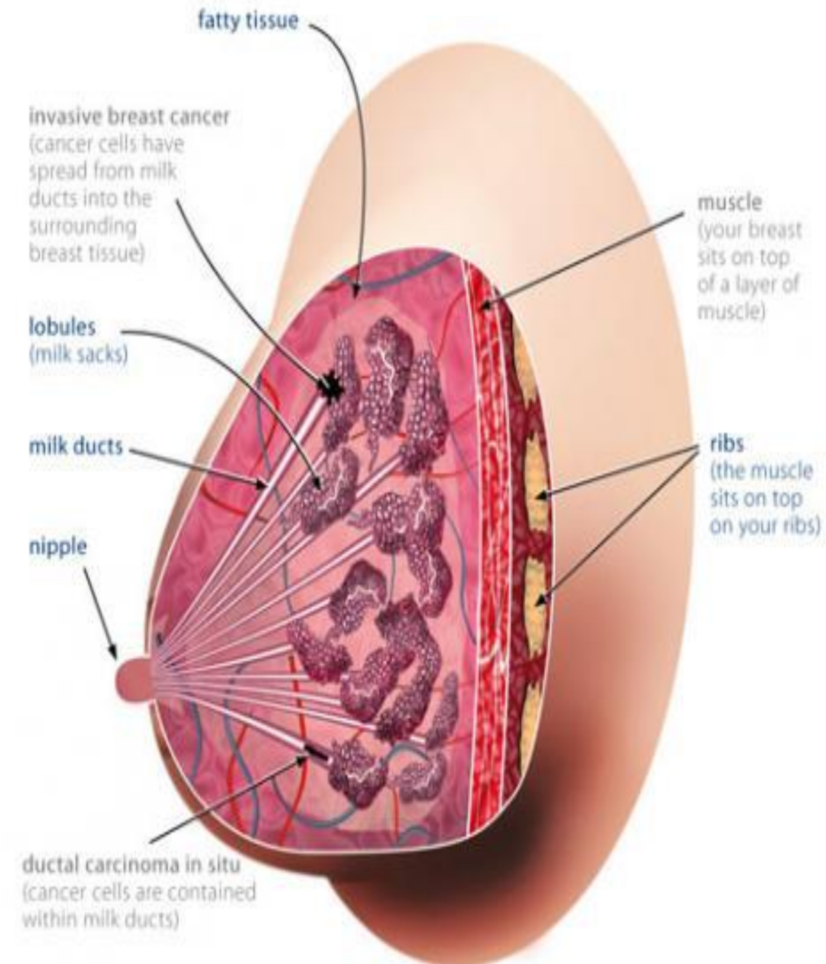
RATIONALE/ BACKGROUND

- DCIS is a pre-invasive malignancy of the breast
- ≈ 20% of screen detected breast cancers
- Progression rate to invasive breast cancer is highly variable (14-53%)
- Almost always treated as invasive breast cancer



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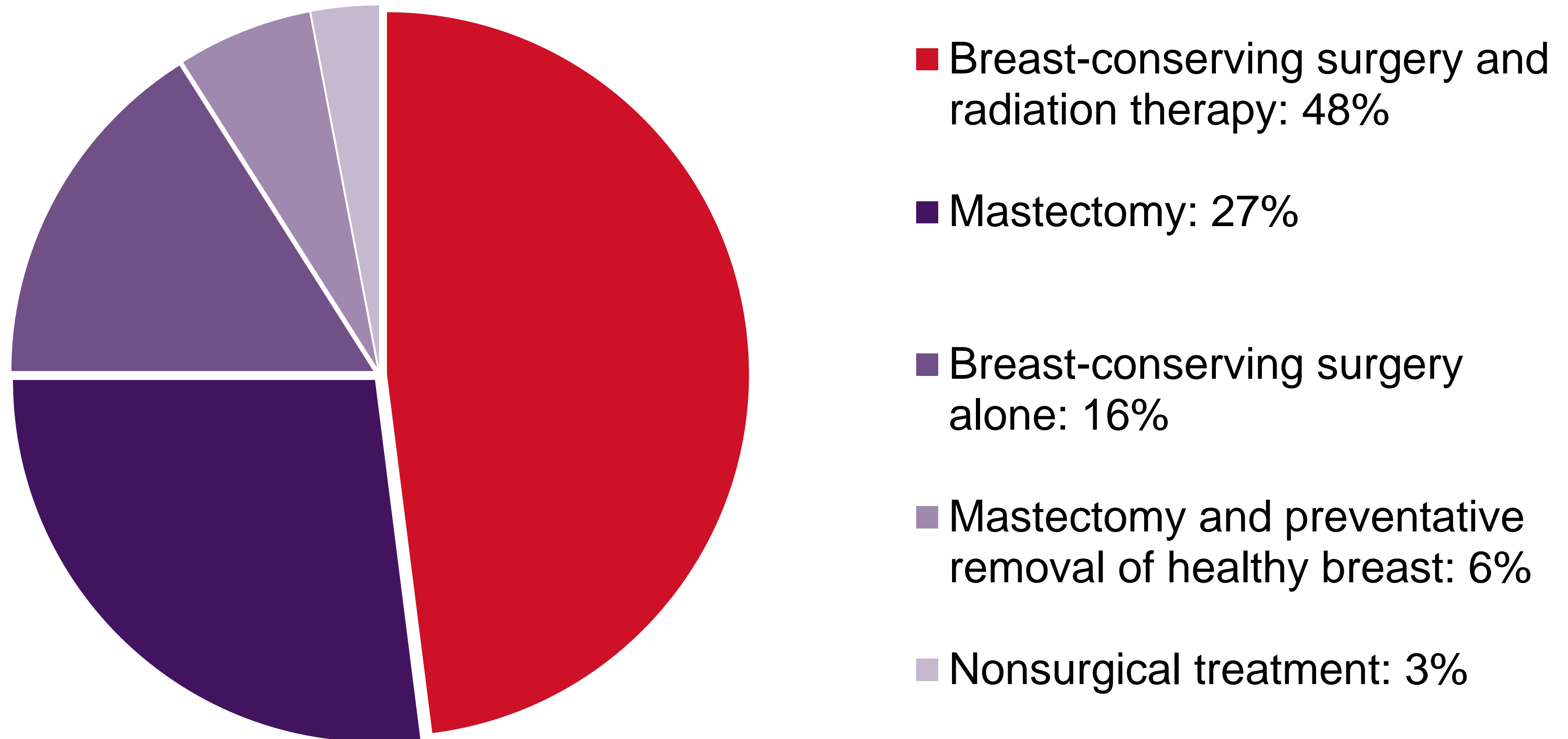
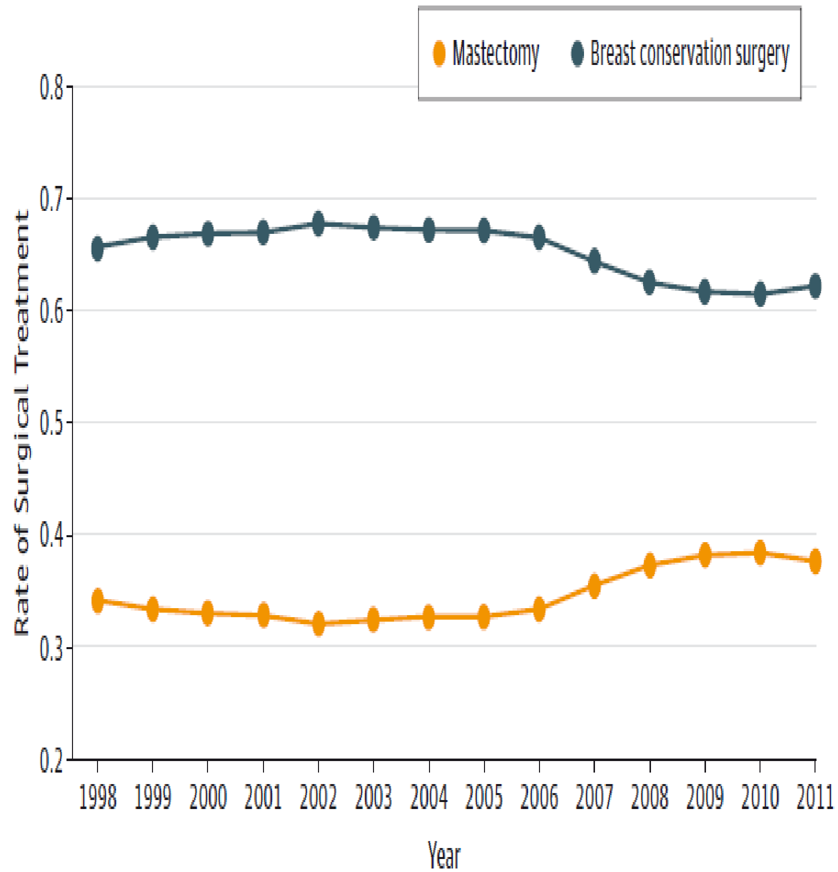
RATIONALE/ BACKGROUND

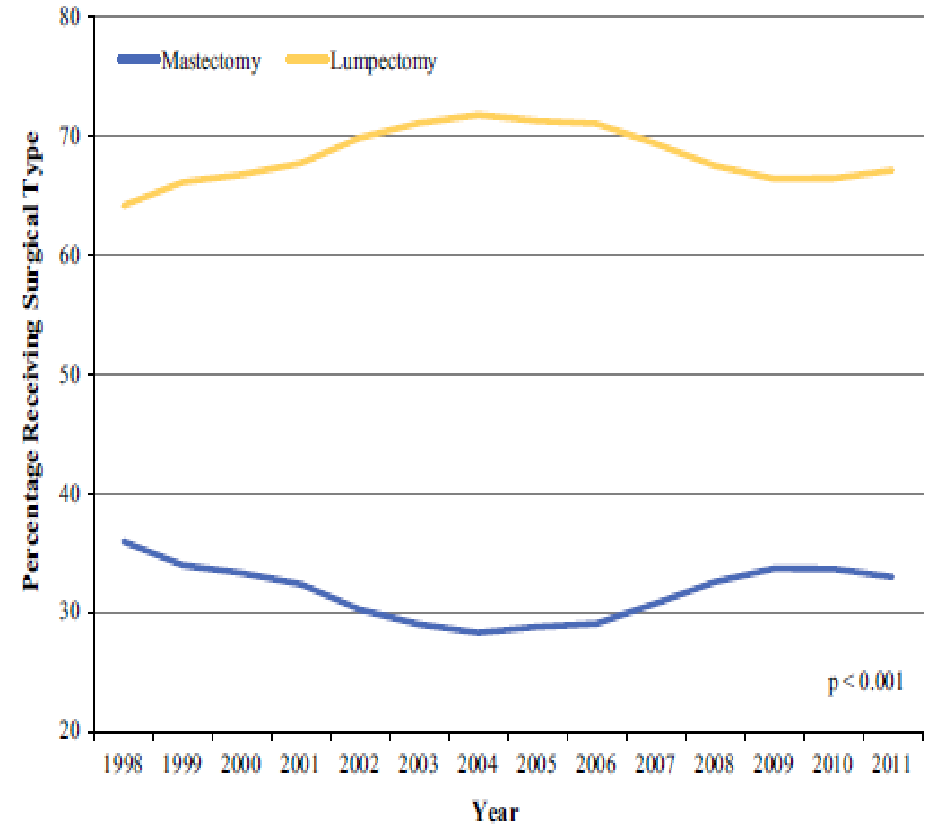


Most women are treated with lumpectomy + radiation therapy or mastectomy with an increasing rate of mastectomy and bi-lateral mastectomy

(Tuttle, 2009; Gomez, 2010; Kummerow, 2014; Rutter, 2015)

RATIONALE/ BACKGROUND





Kummerow, 2014; Rutter, 2015

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PATIENTS MISUNDERSTAND DCIS

- Women with DCIS confused about whether or not they had a cancer that could result in death (DeMorgan, 2002)
- Use of different terms confusing (DeMorgan, 2011)
- 87% of women diagnosed with DCIS do not understand that DCIS cannot spread to other parts of the body (Davey, 2011)

POOR DR-PATIENT COMMUNICATION

- The majority of clinicians "always" or "almost always" describe DCIS as cancer (Partridge, 2008)

- Diverse perceptions of DCIS and the terminology used varies considerably (Kennedy, 2009)

- Little consensus exists on how best to explain DCIS to patients (Fallowfield, 2014)

THE CANCER TERM

"The word 'cancer' is used to describe an ever broader spectrum of behaviour; but the word retains its fearsome quality, sometimes corrupting thought and action…Healthy people are quickly converted to cancer patients, and toxic interventions are offered and accepted"

(Dunn, 2013)

REMOVING THE CANCER TERM

DOI: 10.1093/jnci/djp485
Advance Access publication on January 13, 2010.
Published by Oxford University Press 2010.

National Institutes of Health State-of-the-Science Conference Statement: Diagnosis and Management of Ductal Carcinoma In Situ September 22–24, 2009

Carmen J. Allegra, Denise R. Aberle, Pamela Ganschow, Stephen M. Hahn, Clara N. Lee, Sandra Millon-Underwood, Malcolm C. Pike, Susan D. Reed, Audrey F. Saftlas, Susan A. Scarvalone, Arnold M. Schwartz, Carol Slomski, Greg Yothers, Robin Zon

Manuscript received November 5, 2009; accepted November 30, 2009.

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Foreword
National Institutes of Health consensus and state-of-the-science staten
and public representatives on the basis of 1) the results of a systema
Healthcare Research and Quality, 2) presentations by investigators wo
public session, 3) questions and statements from conference attende
sion, and 4) closed deliberations by the panel during the remainder o
independent report of the panel and is not a policy statement of the N

The statement reflects the panel's assessment of medical know
provides a "snapshot in time" of the state of knowledge on the confe
knowledge is inevitably accumulating through medical research.

Objective To provide health-care providers, patients,
rently available data on the diagnosis and m

Participants A non-Department of Health and Human Ser
oncology, radiology, surgery (general and reco
idemiology, biostatistics, nursing, obstetrics ar
social work. In addition, 22 experts from pertin

Evidence Presentations by experts and a systematic
based Practice Center, through the Agency
given precedence over anecdotal experienc

Conference process The panel drafted its statement based on s
scientific literature. The draft statement was
the audience for comment. The panel release
This statement is an independent report o
Institutes of Health or the Federal Governm

Conclusions Clearly, the diagnosis and management of I
cluding the fundamental natural history of u
coupled with its favorable prognosis, strong
anxiety-producing term "carcinoma" from t
available therapies are excellent. Thus, the
rate identification of patient subsets diagnos
with less therapeutic intervention without sacrificing the excellent outcomes presently achieved. Essential in this quest will be the development and validation of accurate risk stratification methods based on a comprehensive understanding of the clinical, pathological, and biological factors associated with DCIS.

J Natl Cancer Inst 2010;102:161–169

Ductal carcinoma in situ of the breast, or DCIS, represents a spectrum of abnormal cells confined to the breast duct and is a risk factor for invasive breast cancer development. Unlike invasive breast cancer, DCIS either has not yet invaded beyond its intraductal origin or may never invade neighboring tissues. DCIS is most often diagnosed as a consequence of screening for invasive breast cancer because DCIS has no specific screening modality. The etiology of DCIS is presumably heterogeneous, making

***Panel*: Consensus of the working group recommendations regarding overdiagnosis and overtreatment presented to the National Cancer Institute**

1. Recognise that overdiagnosis occurs and is common
2. Embrace the development of new terminology to replace the word cancer when appropriate, when data or companion diagnostics support the classification of low-risk lesions as indolent lesions of epithelial origin (IDLEs)
3. Create observational registries for IDLEs and disorders with low or uncertain risk of progression to cancer
4. Mitigate overdiagnosis by testing strategies that lower the chance of detecting unimportant lesions
5. Embrace new concepts for how to approach cancer progression and prevention

RESEARCH QUESTION

How does different terminology to describe DCIS affect women's psychological responses and management preferences?

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METHODS

- Qualitative study using semi-structured telephone interviews
- Community sample of 26 Australian women aged 25-80 years varying by education and cancer screening experience
- Participants responded to a hypothetical scenario using terminology <u>with</u> and <u>without</u> the cancer term to describe DCIS
- We explored women's concern and treatment preference (acceptability of watchful waiting vs immediate treatment)
- Thematic analysis was used to analyse the data

Description of DCIS and management options

Breast screening (mammograms) detects changes of the cells in the breast as well as finding breast cancers. In some women these ***[abnormal cells/pre-invasive breast cancer cells]*** *can progress to invasive cancer and in others they do not. It's estimated that if left untreated about one-third may progress to breast cancer over 10 years or more. This means that for about two-thirds of women, these* ***[abnormal cells/pre-invasive breast cancer cells]*** *may not become cancer.*

[Abnormal breast cells/pre-invasive breast cancer cells] *are usually treated by surgery, radiation or drugs as in the case of breast cancer. Another approach is called watchful waiting, where doctors closely monitor the* ***[abnormal breast cells/pre-invasive breast cancer cells]*** *with regular mammograms and only treat if cells become more abnormal.*

RESULTS

Reactions to Cancer vs. Non-cancer terminology

- **High concern about a DCIS diagnosis regardless of the terminology used**

  "I'd be extremely concerned because I wouldn't know which third I fell in." (ID6, age 58, HE)

- **Stronger reactions to the cancer terminology**

  "I'd probably be more concerned. It has the word cancer." (ID3, age 57, LE)

- **Preferred the diagnosis to be given as a description of abnormal cells**

  "I'd be comfortable having it discussed as a description of abnormal cells." (ID5, age 62, HE)

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RESULTS
Attitudes about watchful waiting

- **Many women interested in watchful waiting to manage their DCIS**

  "I don't think I'd want to have any treatment. Unless it was actually necessary." (ID8, age 58, LE)

- **Feeling informed and involved in decision making gave women additional confidence in choosing watchful waiting**

- **However, a higher frequency of monitoring was preferred by women**

  "At six months I'd want it retested and checked to make sure that nothing has progressed." (ID15, age 47, HE)

UNDERSTANDING OUR QUANT STUDY

- National community survey with 282 women
- Hypothetical scenario switching the terminology used for DCIS
- Results:
  - High level of overall initial concern
  - Level of concern decreased with use a non-cancer term
  - Overall (64%) women were interested in managing their hypothetical DCIS with watchful waiting
  - Acceptability of watchful waiting increased when a non-cancer term was used to describe DCIS

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LIMITATIONS

- Hypothetical scenario – what would happen in clinical practice is still unknown

- Estimated population average for the risk of progression from DCIS to invasive cancer
  - In practice, risk of progression vary by age, family history of breast cancer and tumour grade
  - Individually tailored information would be given to patients

- Watchful waiting is not currently a management option supported by all clinicians

IMPLICATIONS FOR ADDRESSING OVERTREATMENT

Descriptions that do not include the cancer term *may*

- help decrease women's concern and anxiety
- increase willingness to consider watchful waiting

Together this may help support informed decision making for management of DCIS and in turn reduce unnecessary aggressive treatments

THANK YOU

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