Guidelines and practice in the U.S. for women at high risk for breast cancer, and the impact of the media

Robert A. Smith, PhD
American Cancer Society
Atlanta, GA USA

Incidence rates of breast cancer among women with a *BRCA1* mutation vary according to their reproductive histories and country of residence.

Country			
Risk	Poland	Norway	North America
Average annual Risk	1.4%	2.0%	2.4%
Risk to age 50	35%	40%	58%
Risk to age 70	55%	61%	69%

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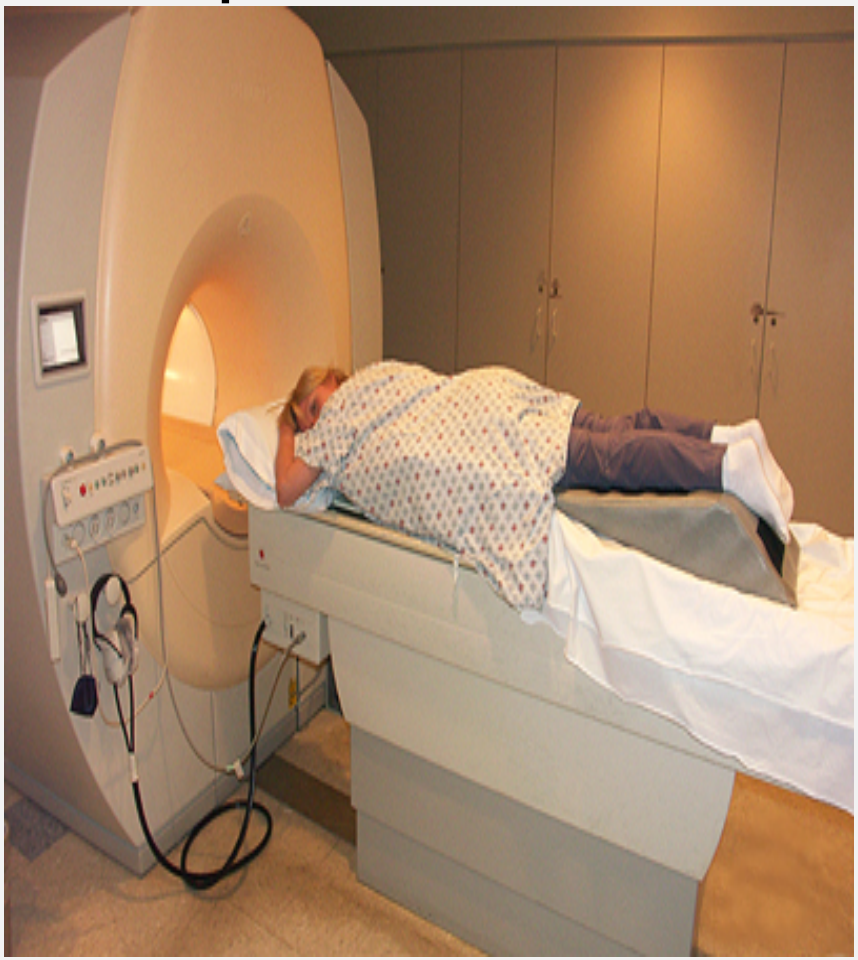
Early onset of breast cancer in women at inherited risk has led to recommendations for more aggressive surveillance protocols



American Cancer Society Guidelines for Breast MRI in High Risk Women (2007)

TABLE 1 Recommendations for Breast MRI Screening as an Adjunct to Mammography

Recommend Annual MRI Screening (Based on Evidence*)
- *BRCA* mutation
- First-degree relative of *BRCA* carrier, but untested
- Lifetime risk ~20–25% or greater, as defined by BRCAPRO or other models that are largely dependent on family history

Recommend Annual MRI Screening (Based on Expert Consensus Opinion†)
- Radiation to chest between age 10 and 30 years
- Li-Fraumeni syndrome and first-degree relatives
- Cowden and Bannayan-Riley-Ruvalcaba syndromes and first-degree relatives

Insufficient Evidence to Recommend for or Against MRI Screening‡
- Lifetime risk 15–20%, as defined by BRCAPRO or other models that are largely dependent on family history
- Lobular carcinoma in situ (LCIS) or atypical lobular hyperplasia (ALH)
- Atypical ductal hyperplasia (ADH)
- Heterogeneously or extremely dense breast on mammography
- Women with a personal history of breast cancer, including ductal carcinoma in situ (DCIS)

Recommend Against MRI Screening (Based on Expert Consensus Opinion)
- Women at <15% lifetime risk

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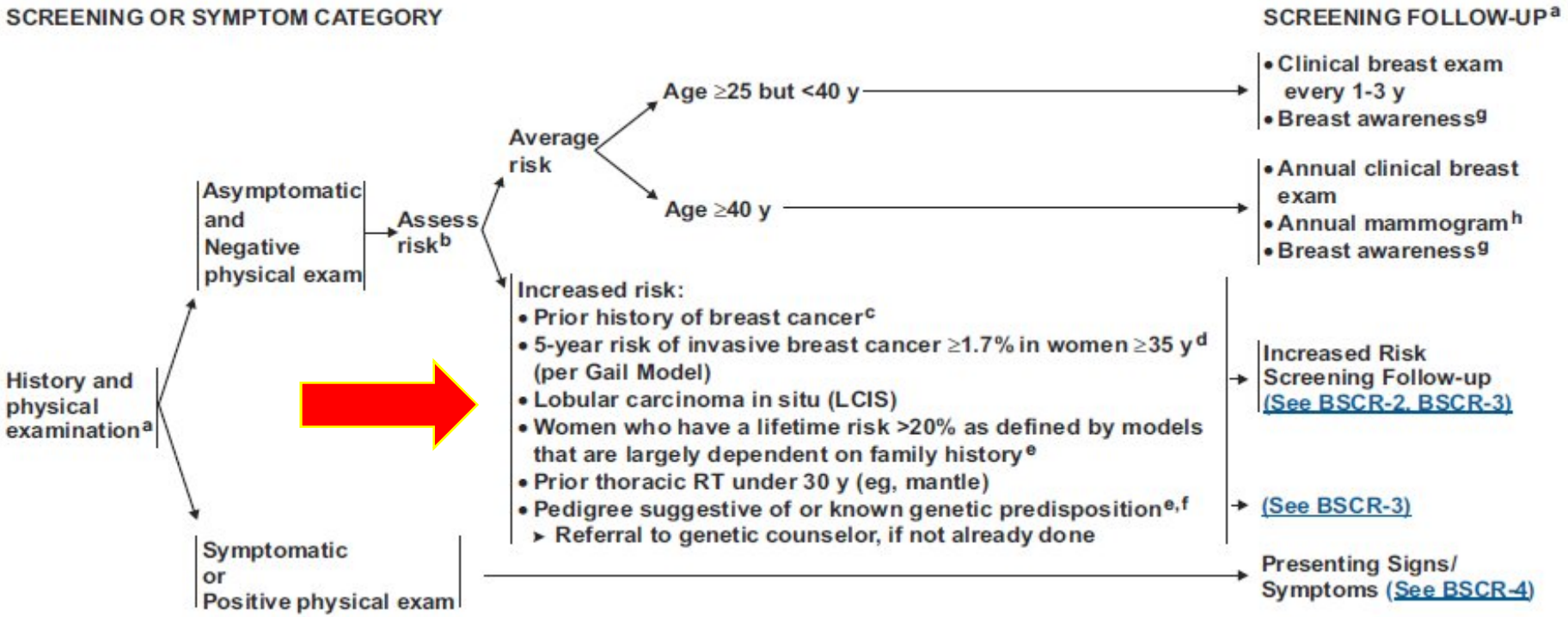

[a] See Breast Screening Considerations (BSCR-A).
[b] Refer to the NCCN Guidelines for Breast Cancer Risk Reduction for a detailed qualitative and quantitative assessment.
[c] See NCCN Guidelines for Breast Cancer - Surveillance Section.
[d] See Risk Factors Used in the Modified Gail Model (BSCR-B).
[e] Risk models that are largely dependent on family history (eg, Claus, BRCAPRO, BOADICEA, Tyrer-Cuzick). See NCCN Guidelines for Breast Cancer Risk Reduction.
[f] There is variation in recommendations for initiation of screening for different genetic syndromes. See NCCN Guidelines for Genetic/Familial High-Risk Assessment.
[g] Women should be familiar with their breasts and promptly report changes to their health care provider. Periodic, consistent breast self exam (BSE) may facilitate breast self awareness. Premenopausal women may find BSE most informative when performed at the end of menses.
[h] See Mammographic Evaluation (BSCR-16).

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

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NCCN Guidelines Version 2.2013
Breast Cancer Screening and Diagnosis

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SCREENING OR SYMPTOM CATEGORY | **SCREENING FOLLOW-UP**

Increased Risk:

Prior history of breast cancer → See NCCN Guidelines for Breast Cancer - Surveillance Section

Women ≥35 y with 5-year risk of invasive breast cancer ≥1.7%[d]
OR
LCIS (begin screening at diagnosis) →
- Annual mammogram[h] + clinical breast exam every 6-12 mo
- Breast awareness[g]
- Consider risk reduction strategies (See NCCN Guidelines for Breast Cancer Risk Reduction)

Women who have a lifetime risk >20% as defined by models that are largely dependent on family history[e] →
- Annual mammogram[h] + clinical breast exam every 6-12 mo
  - beginning at age 30 y
- Breast awareness[g]
- Consider risk reduction strategies (See NCCN Guidelines for Breast Cancer Risk Reduction)
- Consider annual breast MRI
  - beginning at age 30 y

Prior thoracic RT between the ages of 10 and 30 y

Age <25 y →
- Annual clinical breast exam
  - beginning 8 to 10 y after RT
- Breast awareness[g]

Age ≥25 y →
- Annual mammogram[h] + clinical breast exam every 6-12 mo
  - Begin 8-10 y after RT or age 40, whichever comes first
- Recommend annual breast MRI as an adjunct to mammogram and clinical breast exam
- Breast awareness[g]

[d] See Risk Factors Used in the Modified Gail Model (BSCR-B).
[e] Risk models that are largely dependent on family history (eg, Claus, BRCAPRO, BOADICEA, Tyrer-Cuzick). See NCCN Guidelines for Breast Cancer Risk Reduction.
[g] Women should be familiar with their breasts and promptly report changes to their health care provider. Periodic, consistent breast self exam (BSE) may facilitate breast self awareness. Premenopausal women may find BSE most informative when performed at the end of menses.
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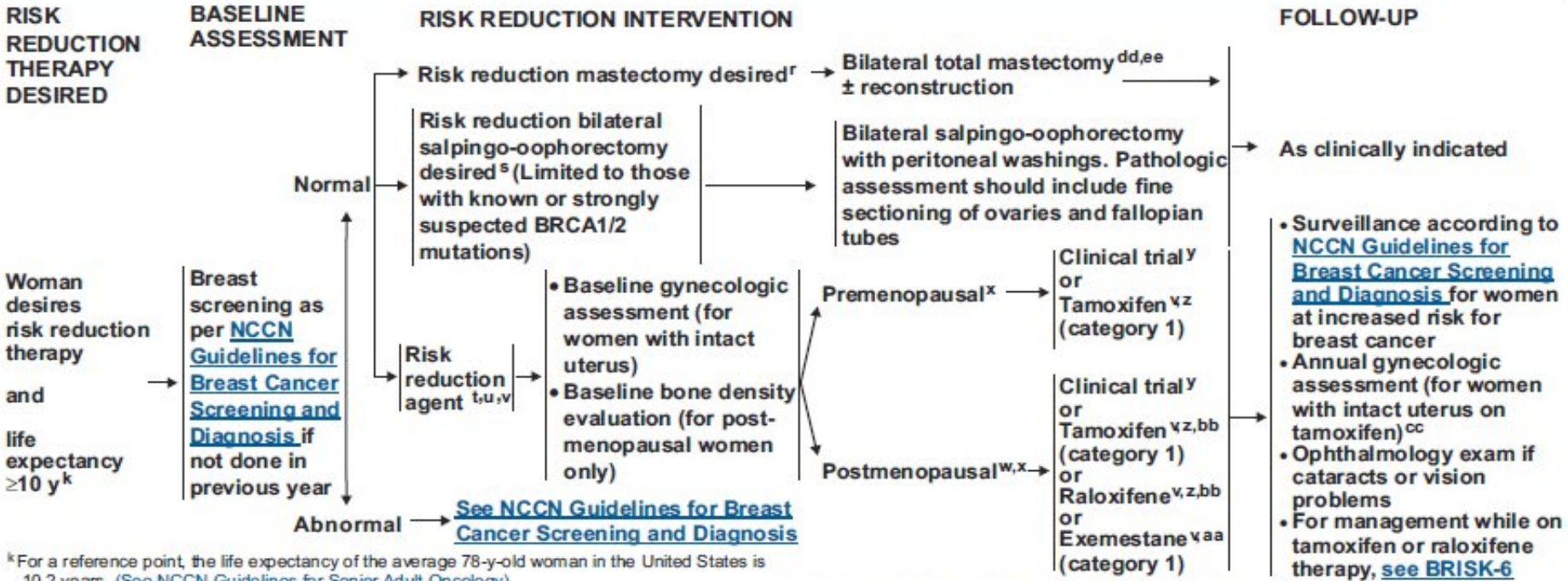
NCCN Guidelines Version 1.2013
Breast Cancer Risk Reduction

NCCN Guidelines Index
Breast Cancer Risk Reduction TOC
Discussion



[k] For a reference point, the life expectancy of the average 78-y-old woman in the United States is 10.2 years. (See NCCN Guidelines for Senior Adult Oncology).

[r] Risk reduction mastectomy should generally be considered only in women with BRCA1/2, or other strongly predisposing gene mutation, compelling family history, or possibly with LCIS or prior thoracic radiation therapy at <30 y of age. Women considering risk reduction mastectomy should receive multidisciplinary counseling including consultation with genetics if not already done. Psychological consultation may also be of value.

[s] The additional benefit of concurrent hysterectomy is not clear at this time.

[t] There are no data regarding the use of risk reduction agents in women with prior thoracic radiation therapy.

[u] CYP2D6 genotype testing is not recommended in women considering tamoxifen.

[v] See Breast Cancer Risk Reduction Agents (BRISK-B).

[w] Bone density may play a role in choice of therapy.

[x] Clinical trials in breast cancer have utilized a variety of definitions of menopause. Menopause is generally the permanent cessation of menses, and as the term is utilized in breast cancer management includes a profound and permanent decrease in ovarian estrogen synthesis. Reasonable criteria for determining menopause include any of the following: Prior bilateral oophorectomy; age ≥60 y; age <60 y; and amenorrheic for 12 or more months in the absence of chemotherapy, tamoxifen, toremifene, or ovarian suppression and FSH and estradiol in the postmenopausal range. If taking tamoxifen or toremifene and age <60 y, FSH and plasma estradiol level in postmenopausal ranges.

[y] Women in clinical trial should have baseline exam, follow-up, and monitoring as per protocol.

[z] Utility of tamoxifen or raloxifene for breast cancer risk reduction in women <35 years of age is unknown. Raloxifene is only for post-menopausal women >35 y. While raloxifene in long-term follow-up appears to be less efficacious in risk reduction than tamoxifen, consideration of toxicity may still lead to the choice of raloxifene over tamoxifen in women with an intact uterus.

[aa] Other aromatase inhibitors have shown prevention of contralateral breast cancer and there are ongoing clinical trials.

[bb] When counseling postmenopausal women regarding the risk/benefit of tamoxifen and raloxifene, refer to tables in Freedman AN, et al. Benefit/risk assessment for breast cancer chemoprevention with raloxifene or tamoxifen for women age 50 years or older. J Clin Oncol 2011;29(17):2327-2333.

[cc] Routine endometrial ultrasound and biopsy are not recommended for women in the absence of other symptoms.

[dd] Discuss risks and benefits of nipple-areolar sparing surgery.

[ee] Axillary node assessment is not part of the risk reduction procedure.

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

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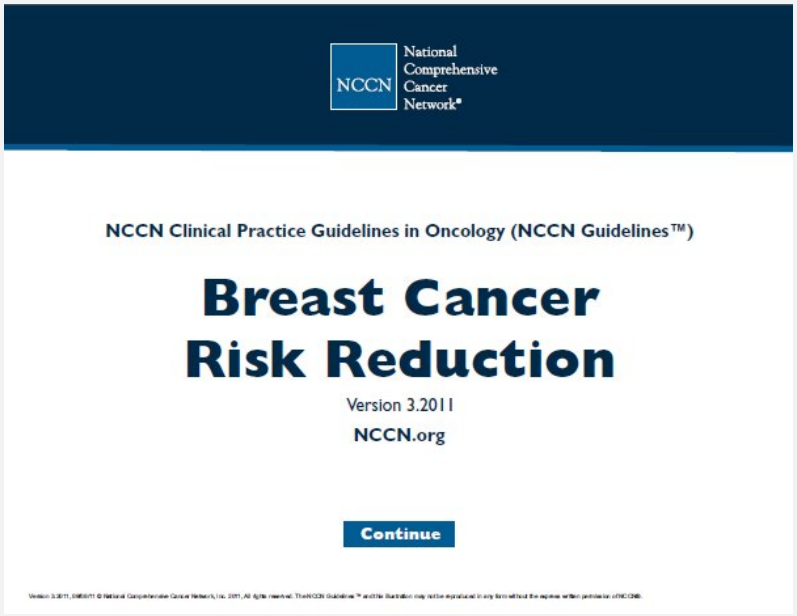
NCCN Guidelines on Risk Reduction Mastectomy



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- Risk reduction mastectomy should generally be considered ***only*** in women with *BRCA1/2*, or other strongly predisposing gene mutation, compelling family history, prior thoracic radiation < age 30, or possibly women with LCIS. Women considering risk reduction mastectomy should receive multi-disciplinary counseling

Celebrities with breast cancer

My Medical Choice, by Angelina Jolie, New York Times, May 14, 2013

OP-ED CONTRIBUTOR

My Medical Choice

By ANGELINA JOLIE

Published: May 14, 2013 | 1712 Comments

LOS ANGELES

Enlarge This Image

MY MOTHER fought cancer for almost a decade and died at 56. She held out long enough to meet the first of her grandchildren and to hold them in her arms. But my other children will never have the chance to know her and experience how loving and gracious she was.

We often speak of "Mommy's mommy," and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told them not to worry, but the truth is I carry a "faulty" gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer.

Loren Capelli

- "I choose not to keep my story private because there are many women who do not know that they might be living under the shadow of cancer. It is my hope that they, too, will be able to get gene tested, and that if they have a high risk they, too, will know that they have strong options."

However…..the media has been criticized for their stories

PHARMA & HEALTHCARE | 12/24/2013 @ 12:23PM | 45,715 views

How The Public And The Media Got Angelina Jolie's Breast Cancer Message Wrong

24 comments, 16 called-out + Comment Now + Follow Comments

Angelina Jolie photo imitating cubist painting style (Photo credit: KiltBear/Flickr)

When the actress and humanitarian wrote a May 14, 2013, *New York Times* op-ed detailing the reasons for her preventative, bilateral mastectomy, I expressed concern that some women with breast cancer might conclude they weren't doing enough to treat their own disease. My reasoning was that the average breast cancer patient, or typical woman assessing her breast cancer risk, might not be able to accurately gauge how their risk of cancer or recurrence compares to Jolie's relatively rare case.

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- News failed to educate the public about genetic risk, and the low percentage of mutation carriers
- News failed to communicate that preventive mastectomy is not recommended for most women

Newspaper Coverage of Angelina Jolie's Prophylactic Bilateral Mastectomy

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ORIGINAL RESEARCH ARTICLE | Genetics inMedicine

Angelina Jolie's faulty gene: newspaper coverage of a celebrity's preventive bilateral mastectomy in Canada, the United States, and the United Kingdom

Kalina Kamenova, PhD[1], Amir Reshef, MBA[1] and Timothy Caulfield, LLM, FRSC[1,2]

Purpose: This study investigates the portrayal of Angelina Jolie's preventive bilateral mastectomy in the news media. Content analysis of print news was conducted to identify major frames used in press coverage, the overall tone of discussions, how journalists report broader questions about *BRCA1/2* testing and hereditary breast/ovarian cancer, and whether they raise concerns about the impact of celebrities on patients' choices and public opinion.

Methods: The Factiva database was used to collect publications on Jolie's preventive mastectomy in elite newspapers in Canada, the United States, and the United Kingdom. The data set consisted of 103 newspaper articles published in the first month of media coverage.

Results: The results show that although the press discussed key issues surrounding predictive genetic testing and preventive options for women at high risk of hereditary breast/ovarian cancer, important medical information about the rarity of Jolie's condition was not communicated to the public.

Conclusion: The results highlight the media's overwhelmingly positive slant toward Jolie's mastectomy, while overlooking the relative rarity of her situation, the challenges of "celebrity medicine," and how celebrities influence people's medical decisions. Future research is required to investigate whether the media hype has influenced demand and use of *BRCA1/2* testing and preventive mastectomies.

Genet Med advance online publication 19 December 2013

Key Words: *BRCA* genetic testing; content analysis; hereditary breast and ovarian cancer; newspapers; preventive mastectomy

INTRODUCTION

On 14 May 2013, Angelina Jolie made headlines throughout the world with the announcement that she was a carrier of a *BRCA1* genetic mutation that significantly increases the risk for breast and ovarian cancer and that she had hence chosen to undergo preventive bilateral mastectomy with reconstructive surgery. In an op-ed piece in *The New York Times*, the actress indicated that the inherited genetic mutation increased her risk for breast cancer to 87% and for ovarian cancer to 50%, and she discussed the medical procedures involved in mastectomies.[1] She also expressed concern that the high cost of *BRCA1/2* testing (suggesting it is "at more than $3,000 in the United States") could limit cancer prevention options for many women.[1] The US National Cancer Institute estimates that women who have inherited a deleterious mutation in the *BRCA1* or *BRCA2* gene are at significantly greater risk for developing breast and/or ovarian cancer than women who do not have such mutations.[2] Data indicate that 55–65% of women with harmful *BRCA1* mutations and 45% of women with harmful *BRCA2* mutations will develop breast cancer during their lives, as compared with only 12% of women in the general population who will develop the disease.[2]

Due to her iconic celebrity status, Jolie's disclosure of her predisposition to hereditary breast/ovarian cancer quickly brought the issues of genetic testing and preventive mastectomy into the limelight. Yet *BRCA1/2* testing has been the subject of continuous policy debate in relation to its cost, access, and clinical benefits.[3] In Canada, concerns in the past have revolved around the inability of the public health-care system to provide comprehensive and timely access to genetic tests and counseling.[4] This was exemplified by the case of Fiona Webster, an Ontario woman who was at risk of hereditary breast cancer but was denied testing. In 1999 she successfully challenged the Ontario Health Insurance Plan to cover *BRCA* screening as an essential medical service.[5] In the United States, the recent Myriad patent controversy has brought the issue of *BRCA1/2* testing to the public's attention, and this type of genetic testing has thereby received significant media coverage.

Physicians and scientists have often been wary of the ways in which the media portray important health issues, particularly the tendency of sensationalism in medical reporting and miscommunication of scientific data, which may diminish the ability of the public to participate as knowledgeable participants in policy debates.[6,7] In the context of genetic research, the term "genohype" has been offered to describe inaccurate portrayals and exaggerated claims about DNA and genetics in the popular media.[8] Although genetic research has been accurately reported in the English-speaking media, news articles have tended to overemphasize benefits and underplay risks of new discoveries.[9] The policy implications of such media

[1]Health Law Institute, Faculty of Law, University of Alberta, Edmonton, Alberta, Canada; [2]Faculty of Law and School of Public Health, University of Alberta, Edmonton, Alberta, Canada. Correspondence: Timothy Caulfield (caulfield@ualberta.ca)

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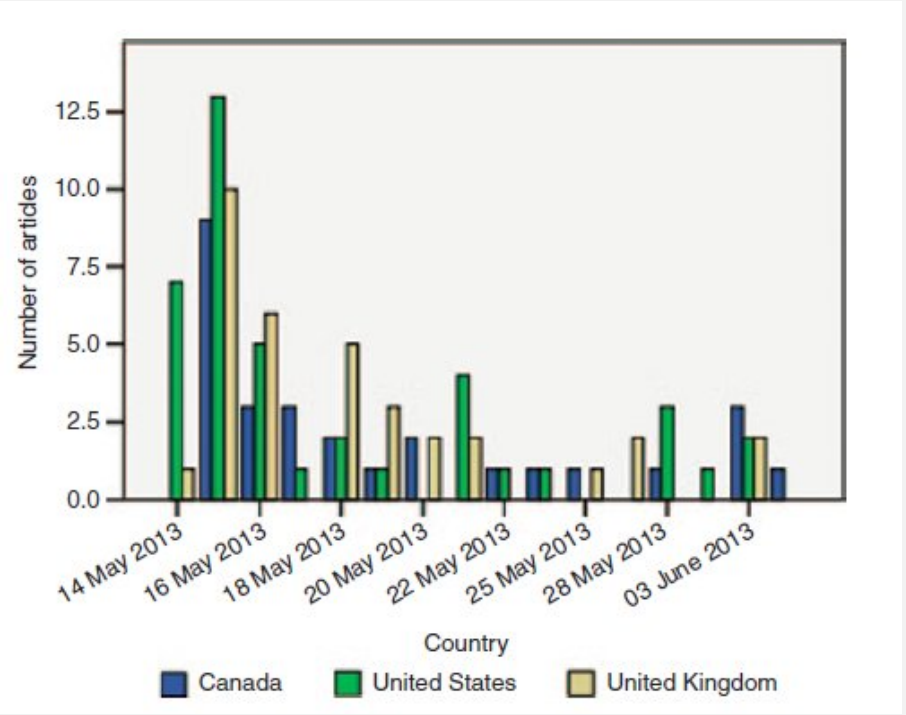
- Mass media & general education system are the primary source of health information to the public:
  - Media is influential in forming beliefs and opinions
  - Media also influences behavior
- Content analysis of "high quality newspaper" stories in 3 countries: U.S., U.K., and Canada one month after New York Time's editorial

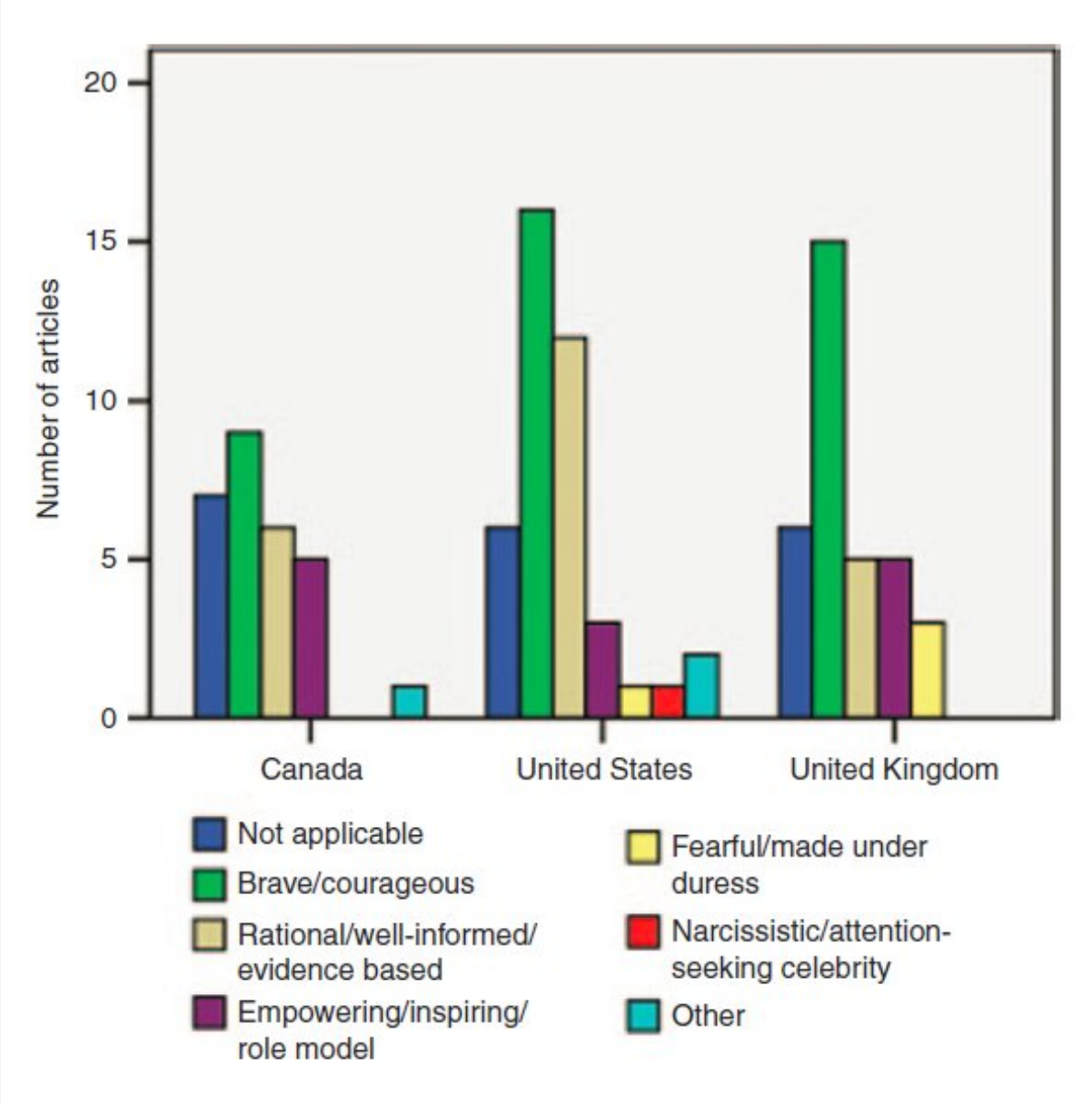
Newspapers in data set

Newspaper	Country	No. of articles	Articles in data set (%)
The Globe and Mail	Canada	9	8.7
The Montreal Gazette	Canada	3	2.9
National Post	Canada	5	4.9
Toronto Star	Canada	9	8.7
Vancouver Sun	Canada	2	1.9
The Los Angeles Times	United States	4	3.9
The New York Times	United States	18	17.5
USA Today	United States	10	9.7
The Wall Street Journal	United States	4	3.9
The Washington Post	United States	5	4.9
The Daily Telegraph	United Kingdom	10	9.7
Financial Times	United Kingdom	3	2.9
The Guardian	United Kingdom	5	4.9
The Independent	United Kingdom	3	2.9
The Times (London)	United Kingdom	13	12.6
Total		103	100

Volume of press coverage by country and Date



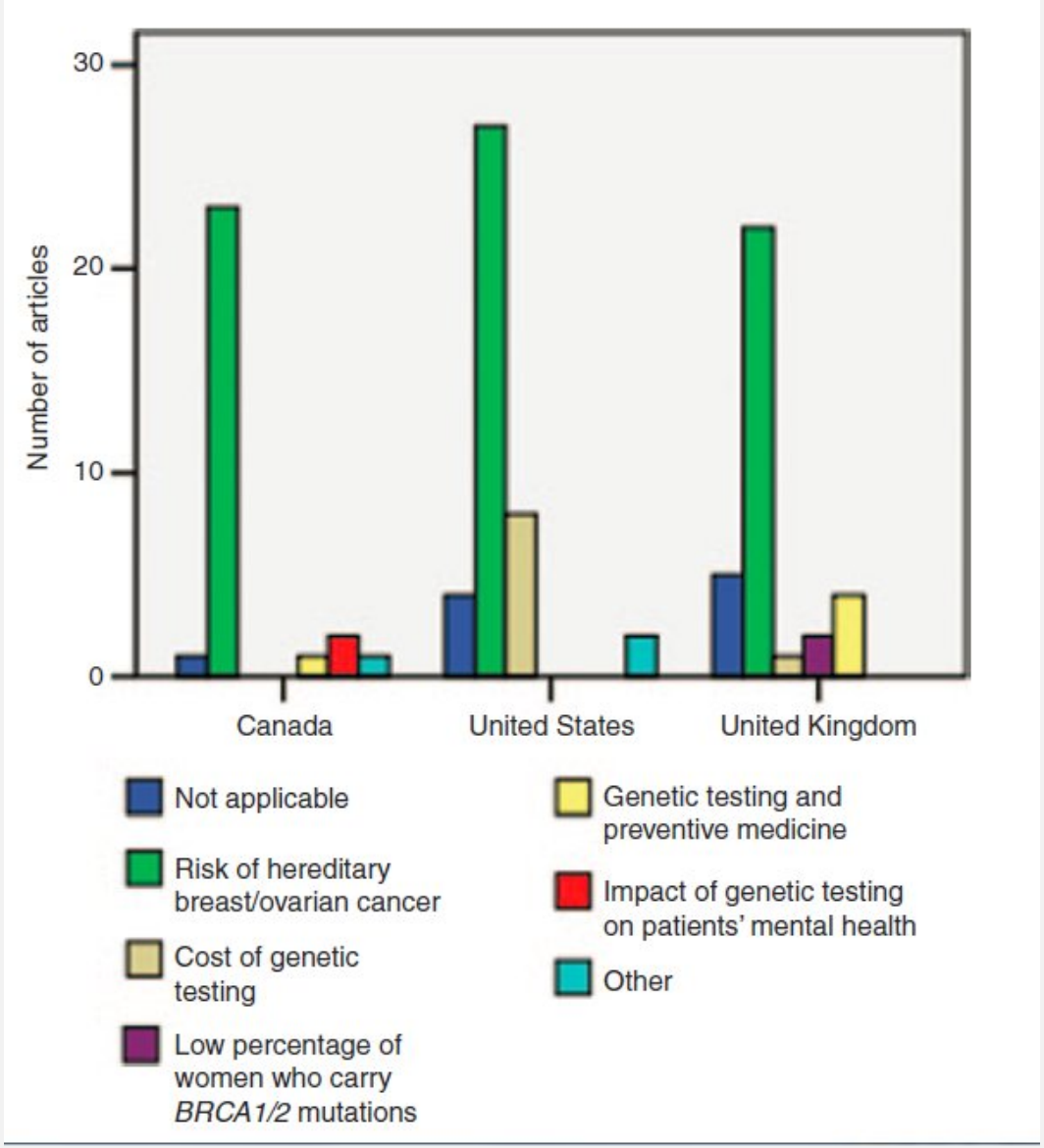
How the Media Framed the Angelina Jolie Story



Most media stories described the decision to have bilateral mastectomy as:

- Brave, courageous
- Rational, well informed and evidence based
- Empowering, inspiring
- Ms. Jolie as a role model

Primary Issue about BRCA1/2 Mutations



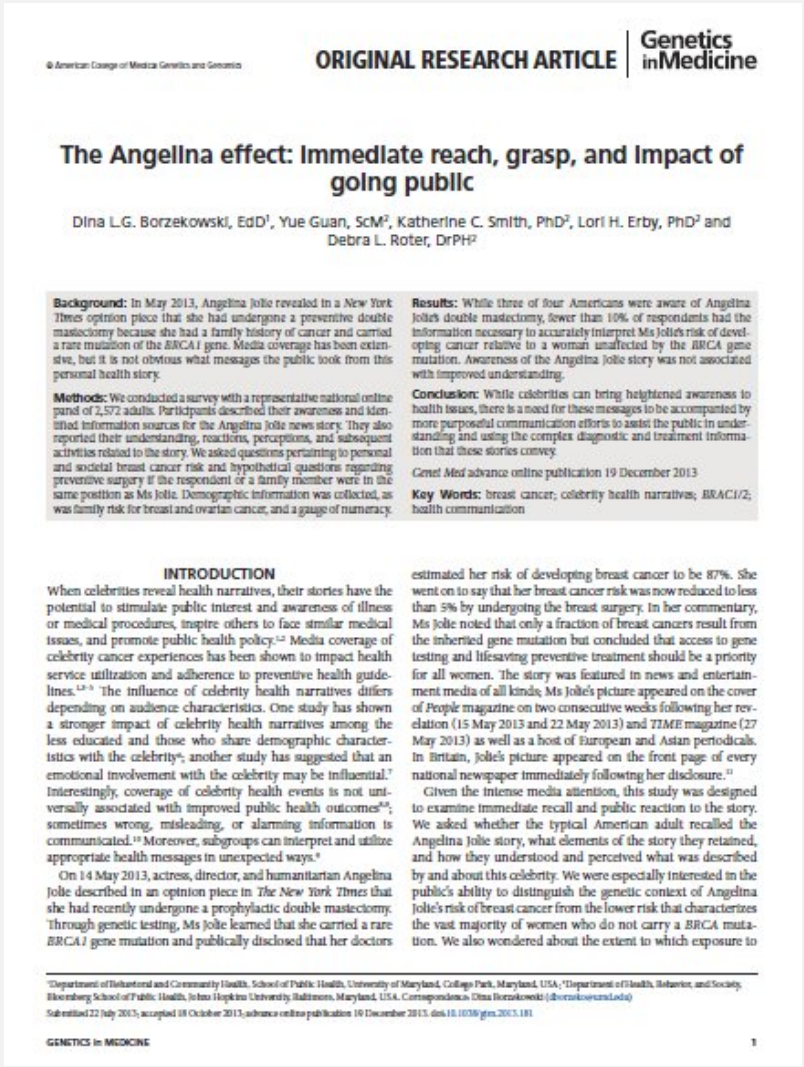
Most media stories focused on genetic risk

Few stories focused put genetic risk vs. average risk or the very low percent of women who carry BRCA1/2 mutations

What issues were missing in the newspaper stories?

- Only 11% of articles cautioned that Angelina Jolie's story could influence women to chose preventive surgery without having an assessment of their genetic risks
- Only 18% of articles mentioned the possible drawbacks of preventive mastectomy

The Impact of Angelina Jolie's Announcement of her Breast Cancer Risk and Decision to Undergo Bilateral Prophylactic Mastectomy



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ORIGINAL RESEARCH ARTICLE | Genetics inMedicine

The Angelina effect: Immediate reach, grasp, and impact of going public

Dina L.G. Borzekowski, EdD[1], Yue Guan, ScM[2], Katherine C. Smith, PhD[2], Lori H. Erby, PhD[2] and Debra L. Roter, DrPH[2]

Background: In May 2013, Angelina Jolie revealed in a *New York Times* opinion piece that she had undergone a preventive double mastectomy because she had a family history of cancer and carried a rare mutation of the *BRCA1* gene. Media coverage has been extensive, but it is not obvious what messages the public took from this personal health story.

Methods: We conducted a survey with a representative national online panel of 2,572 adults. Participants described their awareness and identified information sources for the Angelina Jolie news story. They also reported their understanding, reactions, perceptions, and subsequent activities related to the story. We asked questions pertaining to personal and societal breast cancer risk and hypothetical questions regarding preventive surgery if the respondent or a family member were in the same position as Ms Jolie. Demographic information was collected, as was family risk for breast and ovarian cancer, and a gauge of numeracy.

Results: While three of four Americans were aware of Angelina Jolie's double mastectomy, fewer than 10% of respondents had the information necessary to accurately interpret Ms Jolie's risk of developing cancer relative to a woman unaffected by the *BRCA* gene mutation. Awareness of the Angelina Jolie story was not associated with improved understanding.

Conclusion: While celebrities can bring heightened awareness to health issues, there is a need for these messages to be accompanied by more purposeful communication efforts to assist the public in understanding and using the complex diagnostic and treatment information that these stories convey.

Genet Med advance online publication 19 December 2013

Key Words: breast cancer; celebrity health narratives; *BRAC1/2*; health communication

INTRODUCTION

When celebrities reveal health narratives, their stories have the potential to stimulate public interest and awareness of illness or medical procedures, inspire others to face similar medical issues, and promote public health policy.[1,2] Media coverage of celebrity cancer experiences has been shown to impact health service utilization and adherence to preventive health guidelines.[1,2,3] The influence of celebrity health narratives differs depending on audience characteristics. One study has shown a stronger impact of celebrity health narratives among the less educated and those who share demographic characteristics with the celebrity[4]; another study has suggested that an emotional involvement with the celebrity may be influential.[5] Interestingly, coverage of celebrity health events is not universally associated with improved public health outcomes[6,7]; sometimes wrong, misleading, or alarming information is communicated.[10] Moreover, subgroups can interpret and utilize appropriate health messages in unexpected ways.[8]

On 14 May 2013, actress, director, and humanitarian Angelina Jolie described in an opinion piece in *The New York Times* that she had recently undergone a prophylactic double mastectomy. Through genetic testing, Ms Jolie learned that she carried a rare *BRCA1* gene mutation and publically disclosed that her doctors estimated her risk of developing breast cancer to be 87%. She went on to say that her breast cancer risk was now reduced to less than 5% by undergoing the breast surgery. In her commentary, Ms Jolie noted that only a fraction of breast cancers result from the inherited gene mutation but concluded that access to gene testing and lifesaving preventive treatment should be a priority for all women. The story was featured in news and entertainment media of all kinds; Ms Jolie's picture appeared on the cover of *People* magazine on two consecutive weeks following her revelation (15 May 2013 and 22 May 2013) and *TIME* magazine (27 May 2013) as well as a host of European and Asian periodicals. In Britain, Jolie's picture appeared on the front page of every national newspaper immediately following her disclosure.[11]

Given the intense media attention, this study was designed to examine immediate recall and public reaction to the story. We asked whether the typical American adult recalled the Angelina Jolie story, what elements of the story they retained, and how they understood and perceived what was described by and about this celebrity. We were especially interested in the public's ability to distinguish the genetic context of Angelina Jolie's risk of breast cancer from the lower risk that characterizes the vast majority of women who do not carry a *BRCA* mutation. We also wondered about the extent to which exposure to

[1]Department of Behavioral and Community Health, School of Public Health, University of Maryland, College Park, Maryland, USA; [2]Department of Health, Behavior, and Society, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, USA. Correspondence: Dina Borzekowski (dborzeko@umd.edu)

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- Survey of representative national online panel of 2,572 adults conducted within 3 weeks of the story.
- Did the story influence the public's ability to distinguish the genetic context of Angelina Jolie's risk vs. the lower risk of most women?
- Impact on self assessment?
- Impact on information seeking?

Public's Response to Angelina Jolie's Story

- Approximately 3 in 4 adults correctly identified that Angelina Jolie had a bilateral preventive mastectomy
- Almost 1 in 2 adults reported her risk (87%) in the correct range (80-90%)
- Less than 1 in 10 gave accurate answers about BRCA1 mutations and breast cancer risk
- Women's perceptions were less accurate than men's.

Annals of Internal Medicine | ORIGINAL RESEARCH

Perceptions, Knowledge, and Satisfaction With Contralateral Prophylactic Mastectomy Among Young Women With Breast Cancer

A Cross-sectional Survey

Shoshana M. Rosenberg, ScD, MPH; Michaela S. Tracy, BA; Meghan E. Meyer, BS; Karen Sepucha, PhD; Shari Gelber, MS, MSW; Judi Hirshfield-Bartek, MS; Susan Troyan, MD; Monica Morrow, MD; Lidia Schapira, MD; Steven E. Come, MD; Eric P. Winer, MD; and Ann H. Partridge, MD, MPH

- Rates of contralateral prophylactic mastectomy (CPM) have increased dramatically among women treated for early-stage breast cancer in recent years in the United States.
- In the late 1990s, **between 4% and 6%** of women who had mastectomies also underwent CPM, whereas in more recent years the reported range has increased to between **11% and 25%,** a 3- to 4-fold change.

The value of contralateral preventive mastectomy for most women with early stage, unilateral breast cancer is not clear

- Risk of breast cancer in the unaffected breast is reduced, but it is not high at the time of surgery (0.5% -0.75% per year)
- Risk is lower today due to adjuvant therapy
- Survival is not improved compared treatment only of the affected breast
- There also are complications from the procedure

Table 2. **Importance of Reasons Identified by Women for Choosing CPM***

Reason	Extremely Important	Very Important	Somewhat Important	Not at All Important
Desire to lower the chance of getting cancer in other breast	102 (83)	18 (15)	1 (1)	1 (1)
Desire for peace of mind	98 (80)	18 (15)	5 (4)	1 (1)
Desire to improve survival or extend life	97 (79)	18 (15)	3 (2)	5 (4)
Desire to prevent breast cancer from spreading to other parts of body	85 (69)	20 (16)	5 (4)	13 (11)
Feeling at increased risk for cancer in other breast	81 (66)	26 (21)	9 (7)	5 (4)
Worry that screening would not find cancer in other breast	39 (32)	21 (17)	32 (26)	28 (23)
Strong family history of breast cancer	35 (28)	11 (9)	10 (8)	57 (46)
Desire to have both breasts look the same after surgery	34 (28)	36 (29)	34 (28)	18 (15)
Known genetic change, such as *BRCA1* or *BRCA2* mutation	32 (26)	2 (2)	2 (2)	73 (59)
Desire to follow physician's recommendation	22 (18)	16 (13)	35 (28)	45 (37)
Desire to make breasts look better	13 (11)	20 (16)	29 (24)	57 (46)
Advice from family or friends	6 (5)	11 (9)	38 (31)	66 (54)

The main reasons for choosing CPM were to:
(1) Lower risk, (2) Peace of mind, (3) Improve survival, and desire to have breasts look the same

Table 3. **Women's Reported Experiences in Relation to Expectations Associated With CPM***

Outcome	Worse Than Expected	About What Was Expected	Better Than Expected
Cosmetic results	34 (28)	55 (45)	31 (25)
Pain at surgical site	31 (25)	49 (40)	37 (30)
Number of surgeries/procedures needed	41 (33)	68 (55)	10 (8)
Numbness or tingling in chest	35 (28)	63 (51)	19 (15)
Self-conscious about appearance	38 (31)	49 (40)	28 (23)
Sense of sexuality	52 (42)	48 (39)	17 (14)
Worry or anxiety about breast cancer	28 (23)	63 (51)	29 (24)
Amount of follow-up imaging or tests	14 (11)	61 (50)	32 (26)
Recovery from reconstructive surgery†	33 (27)	39 (32)	41 (33)
Complications or problems from reconstructive surgery†	26 (21)	34 (28)	30 (24)
Filling up expanders†	28 (23)	32 (26)	29 (24)

Although a significant fraction of women experience outcomes worse than expected, a majority of women report outcomes as expected or better than expected.

75% report expected or diminished worry and anxiety

Conclusions

- In general, risk identification, risk assessment, and risk communication is not optimal
- Communication by media and doctors is not optimal
- There is a need to better understand factors associated with decision making by women at all levels of risk, and how to improve the role of the clinician as the most trusted source of information

Thank you