Today we celebrate the publication of our 100th XRAY review. It's amazing to think how the program we developed over the past three years has grown to serve over 70,000 people affected by breast cancer. We knew the need was there. We saw how catchy headlines like “BRCA Gene Mutations Also Linked with Salivary Gland Cancer” or “Angelina Jolie Gene May Be Linked to Alzheimer’s, Researchers Say” cause deep concern in our community.

Lesson One: There is no shortage of breast cancer news

When we began developing the XRAY program, we asked ourselves and our steering committee, “Will there be enough relevant breast cancer stories in the media to produce a weekly XRAY review?” Contingency plans were brainstormed, including, “We can write back-up reviews in case there is a week when there is nothing in the media!”

Two years later, we can smile at our past naïve selves and unequivocally say, “Yes, there are more than enough stories on breast cancer research in the media.” From the weekly churn of new research reports to the ood of stories that hit every October, not a week has passed without new research. In fact there are so many stories that our current weekly calendar is filled all the way out until November.

Lesson Two: The headlines are often the worst parts of the stories

Breast cancer news can be complicated—each week it seems like there is a new gene or a new food connected to the disease. But headlines must be short and eye-catching; while media outlets and journalists have good intentions to cover the news as accurately as they can, they also need more readers and more views. Unfortunately, this can cause headlines that may be sensational or shocking, but are misleading or flat out wrong. Over the past few years we have seen good stories that give all the information a patient needs that are ruined by misleading headlines, which are the first thing that patients read. While these headlines may serve as good “clickbait,” they can cause unneeded concern for people facing cancer and their families.

Lesson Three: Some media reports are great, others not so much

We created a rating system to help our community find high-quality articles on breast cancer. In many cases, we saw that stories on the same topic range from high-quality, 5-star articles to more problematic articles with only 1 or 2 stars. This
A sensational article.

Our star rating of the article.

Lesson Four: The media does not always cover the most important stories

Many breast cancer stories involve screening, new drugs, genetic testing, breast cancer risk, and Angelina Jolie. But each week new research on other topics of critical importance to breast cancer survivors, high risk women, and their families are published without any media coverage. Topics such as the financial toxicity of cancer, long term survivorship, metastatic breast cancer, early menopause from treatment or ovary removal, disparities in cancer care, caregiver issues, and much more are important to people facing cancer, but for some reason they are not brought forward as often as they should. The XRAY staff keeps their eyes open for these stories and brings them forward even when very few outlets cover them.

Lesson Five: All cancers deserve an XRAYs program

Funding for the XRAY program comes from the Centers for Disease Control. The funding mechanism that supports XRAY is geared towards young breast cancer survivors (diagnosed before age 45), young women at high risk for breast cancer, and their caregivers and families. Because this is our sole focus, we miss many important articles on other cancers. In the near future, we plan to expand XRAY to other cancers and encourage everyone to look at media coverage with a critical eye.

Final Thought: We could not do this without help from our friends

The XRAY program benefits from a diverse steering committee, including members from Living Beyond Breast Cancer, Tigerlily, Young Survival Coalition, the Gulf States Young Breast Cancer Survivor Network, Stanford University Medical School, University of South Florida, as well as journalists and young survivors. We have received not only funding but also fantastic guidance from the Centers for Disease Control. Most importantly, we appreciate everyone in our community who comments on our reviews, shares them with their social networks, and continues to support XRAY.

XRAY and beyond.

Brian Greene, an American physicist once said, "I believe the process of going from confusion to understanding is a precious, even emotional, experience that can be the foundation of self-confidence." We hope the XRAY program has helped you go from confusion to self-confidence. We thank Lisa Rezende and Julie Huynh for the first 100 XRAY and hope that you are looking forward to future XRAY from our new Vice President of Education, Piri L Welch, PhD.

Posted in: XRAY
Tags: BRCA, Hereditary Cancer, Breast Cancer, Young Survivor, HBOC, PALB2, ATM, Health Journalism, Breast Cancer Risk, Young Onset Breast Cancer
Article: What “The Truth About Cancer” got wrong about BRCA mutations and cancer

SUMMARY

A website called thetruthaboutcancer.com, created a 9-part docu-series titled “The Truth About Cancer: A Global Quest” (TACGQ). The video states that Angelina Jolie’s decision to remove her breasts was one made out of fear; one commentator states that her decision was “barbaric.” This video contains a lot of dangerous misinformation about BRCA mutations and inherited cancer. FORCE XRAYS provides the following point-by-point analysis on “The Truth About Cancer.” (11/10/2015)

Contents

- Epigenics
  - How genes work
  - Epigenics and BRCA
- Inherited mutations
  - Guidelines
  - Resources

This article is also relevant for:

- Preivors
- People with a genetic mutation linked to cancer risk
- Breast cancer survivors
- Women under 45
- Women over 45

TACGQ video

The video’s argument centers on epigenetics, which is explained as something that acts on your genes. The analogy given in the video is, “Your genetics is your software and something has to open it up and read it.”
Further discussion states how epigenetics allows you to turn your genes on and off.

Science

Epigenetics is an active area of biology research that studies how genes can be switched “on” and “off” by external factors. Genes are the instructions used by your body’s cells to make proteins and other molecules that carry out cellular work. Cells have many ways to control genes (or turn them on and off)—it is neither efficient or desirable to have every possible protein made all of the time. If an external factor prevents the gene from making the protein, one can say the gene is “turned off.” However, this does not apply to deleterious BRCA gene mutations because the issue is not whether or not the gene is “turned on or off.” Rather, the issue is that these mutations are incorrect instructions.

Regardless of epigenetics, mutated genes CANNOT make a proper protein because the instructions to make it are wrong from the start. Turning a mutated BRCA gene “on” or “off” does not affect cancer risk. If a light bulb has no conductive wires, flipping the switch will not turn the light on; conversely, switching it off will not work either—nothing will change because the light bulb remains damaged and lacks the necessary components to function. That is why an epigenetic external factor cannot turn a mutated BRCA gene on and off—the gene is already broken and no external influence can manipulate it so that it works again.

TACGQ video:

Claiming that doctors would like you to believe that cancer is genetic and arises from a genetic predisposition, the video states, “Let’s say that your body and your genetics is the computer. That is the hardware. The epigenetics is the software. The software runs the hardware. What we need to do is not dwell on the genetics, but the epigenetics.” But this claim is incorrect and untrue.

Science:

All cancer is considered genetic because it is caused by damage to genes that are either inherited or occur with age. When the genes that control cell growth and division are damaged, cells no longer have instructions to control their growth, and these errors sometimes cause the cells to become cancerous. If you apply the video’s analogy to people with BRCA mutations, the software cannot control the hardware if the hardware is already broken.

How genes work

TACGQ video:
The video also says that genes do not control life. It states that you can activate and deactivate genes, and that if you deactivate your genes with a healthy lifestyle, you do not get cancer.

Science:

Our genes do control life. Our environment, including lifestyle, can affect when genes are turned on and off, but ultimately it is the combination of our genetics AND our environment that have ultimate influence. External environmental factors affect our genes, but cannot change a malfunctioning gene into one that functions properly. While it is important to live a healthy lifestyle, that does not automatically deactivate “bad” genes or activate “good ones.”

Epigenics and BRCA mutations

TACGQ video:

The video says that our epigenetic influences turn genes on and off, so you don’t have to worry about the genes you inherit from your parents.

Science:

Inherited BRCA mutations are present in every cell of the body and cannot be turned on and off by environmental factors.

TACGQ video:

The video claims that the way women live their lives will alter their BRCA mutations.

Science:

Drinking alcohol and obesity are risk factors for breast cancer, while exercise is a protective factor, both for people who do and do not have BRCA mutations. Although unhealthy habits may increase risk, healthy habits do not eliminate anyone’s risk of breast cancer. Avoiding alcohol and getting enough exercise does not affect the BRCA mutation itself, and currently, we have no convincing evidence that diet, exercise, or other lifestyle choices will significantly change the cancer risk for a person with a BRCA mutation. However, healthy lifestyle choices can improve quality of life for cancer survivors and those at high risk for cancer.

Inherited mutations

TACGQ Video:

The video avoids answering the question about whether BRCA mutations can be inherited, and instead talks about how we can turn genes on and off depending on what we eat and how well we sleep.
Science:

BRCA mutations are inherited. Fathers and mothers who carry a BRCA mutation have a 50 percent chance of passing it along to each of their children.

It is important to note that none of the people who provided information for the video are medical oncologists. Ultimately, “The Truth About Cancer: A Global Quest” is full of misleading information that is not grounded in science. This type of misinformation is dangerous, because it may lead high-risk women to drawing incorrect and dangerous conclusions about their ability to prevent cancer through healthy lifestyle alone.

A healthy lifestyle, diet, and exercises are beneficial to everyone—cancer survivors, previvors, and those of average cancer risk. However, the cancer risk for people who have mutations in BRCA or other genes associated with hereditary cancer is greatly increased. National guidelines outline screening and risk management options. If you have a mutation, or you are concerned that your cancer or the cancer in your family is hereditary, please discuss your risk management options with your health care provider.

References

The Truth About Cancer website (note: access to the documentary requires registration).

Posted 11/10/15

NCCN guidelines recommend genetic counseling and testing for people without cancer who have the following family history:

- A relative who has tested positive for an inherited mutation in a gene that increases cancer risk.
- One or more first- or second-degree relatives with breast cancer and any of the following:
  - diagnosed at age 45 or younger
  - triple-negative breast cancer
  - two separate breast cancers, with the first diagnosis at age 50 or younger
  - male breast cancer
- One or more first- or second-degree relatives with:
  - colorectal cancer before age 50
  - endometrial cancer before age 50
  - ovarian, fallopian tube, primary peritoneal cancer
  - rare or childhood cancers

https://www.facingourrisk.org/XRAY/truth-about-cancer-series
One or more first-degree relatives with:
- metastatic or high-grade prostate cancer
- pancreatic cancer

Two or more relatives on the same side of the family diagnosed with any combination of the following at any age:
- breast cancer
- pancreatic cancer
- prostate cancer
- melanoma
- sarcoma
- adrenal cancer
- brain tumors
- leukemia
- endometrial cancer
- thyroid cancer
- kidney cancer
- diffuse gastric cancer
- colon cancer

Updated: 12/04/2021

The American Cancer Society (ACS) guidelines on exercise, nutrition and weight for cancer prevention recommend the following:

**Diet and nutrition**

- Follow a healthy eating pattern, which includes:
  - foods that are high in nutrients in amounts that help you get to and stay at a healthy body weight.
  - a variety of vegetables, fiber-rich legumes (beans and peas), and whole fruits in a variety of colors. ACS recommends people consume at least 2½ to 3 cups of vegetables and 1½ to 2 cups of fruit each day, depending on your calorie requirements.
  - whole grains rather than refined grains. ACS recommends that at least ½ of your grain consumption consists of whole grains.
  - A healthy eating pattern limits or does not include:
    - red and processed meats.
    - sugar-sweetened beverages. ACS recommends that
- highly processed foods and refined grain products
- It is best not to drink alcohol. People who do choose to drink alcohol should:
  - have no more than 1 drink per day for women or 2 drinks per day for men.

**Exercise**

- Exercise regularly.
  - Physical activity has been shown to lower the risk of several types of cancer, including breast, endometrial, prostate and colon cancer. It also reduces the risk of other serious diseases such as diabetes and heart disease.
  - Adults should get at least 150 minutes of moderate-intensity activity (equal to a brisk walk) or 75 minutes of vigorous activity (makes your heartbeat and breathing faster and makes you sweat) each week, preferably spread throughout the week.

**Weight**

- Get to and stay at a healthy weight.
  - Being overweight or obese is a risk factor for many cancers, including breast, colon, endometrial and pancreatic cancer. You can control your weight through regular exercise and healthy eating.

Other experts, including the following, also provide guidelines for exercise, nutrition and health:

- [The Academy of Nutrition and Dietetics](https://www.eatright.org)
- [The United States Office of Disease Prevention and Health Promotion](https://www.cdc.gov)
- [The American Institute for Cancer Research](https://www.aicr.org)

**Questions to Ask Your Doctor**

- Should I have genetic testing for an inherited mutation?
- Can my diet and lifestyle help me prevent cancer?
- What else can I do to lower my risk for cancer?
Health care providers who are specially trained in genetics can help you more clearly understand your risk for hereditary cancer. The following resources can help you locate a genetics expert in your area.

- The National Society of Genetic Counselor website offers a searchable directory for finding a genetic counselor by state and specialty. To find a genetic counselor who specializes in cancer genetics, choose "cancer" under the options "Area of Practice/Specialization."
- InformedDNA is a network of board-certified genetic counselors providing this service by telephone. They can also help you find a qualified expert in your area for face-to-face genetic counseling if that is your preference.
- JScreen is a program from Emory University that provides low-cost genetic counseling and testing.
- Grey Genetics provides access to genetic counselors who offer genetic counseling by telephone.
- The Genetic Support Foundation offers genetic counseling with board-certified genetic counselors.
- FORCE’s toll-free helpline at: 866-288-RISK, ext. 704 will connect you with a volunteer board-certified genetic counselor who can answer general questions about genetic testing and cancer and help you find a genetics expert near you.
- FORCE Peer Navigator Program will match you with a volunteer who has undergone genetic counseling and can help you navigate resources to find a genetic counselor near you.
- Ask your doctor for a referral to a genetics expert.

Updated: 11/12/2021
The following organizations have resources related to genetic counseling and testing.

- FORCE related resources:
  - Information: [What is genetic testing?](#)
  - Information: [How to get genetic testing](#)
  - Information: [Hereditary cancer, genes and risk](#)
  - Personalized portal: [Genetic testing](#)
  - XRAY category: [Genetic testing](#)
  - Video: [ABC of Cancer Genetics](#)
  - Video playlist: [Genetic testing](#)
  - Blogs: [Genetic testing](#)
  - National Society of Genetic Counseling
  - JScreen

Updated: 12/05/2021
Personal Story: Dogs: Companions, hunters, and cancer detectors?

SUMMARY

In August 2016, many news outlets published stories about how actress Shannen Doherty’s dog was able to sniff out her cancer before she was diagnosed. Is there scientific validity to that claim? (9/616)

STORY AT A GLANCE

"Shannen Doherty Opens Up About Chemo Struggles Through Picture of Her Beloved Dog That Sniffed Out Her Cancer." This title appeared with an article that People magazine published this past August about the Beverly Hills,
90210 actress Shannen Doherty and her dog. The Huffington Post, US Magazine, and Entertainment Tonight also ran similar stories about how her dog was able to smell her cancer.

The report raises the following issue:

Has research been done on dogs smelling cancer?

“The notion that animals, especially those with a highly sensitive sense of smell, such as dogs, can sniff malignant tumors is nothing but awkward,” writes Giuseppe Lippi and Gianfranco Cervellin in their scientific review of canine olfaction (smell) detection of cancer. Shannen Doherty claims that her dog obsessively sniffed at her right side, where her breast cancer was subsequently discovered. Other similar cases dating back to 1989 have been published in the literature as case reports, which are scientific publications based on observations of a single patient.

Other studies have tried to determine whether dogs that are trained to recognize the “scent” of a cancer can correctly sniff out the cancer samples from noncancer samples. There are not many of these studies, and the success of the findings differs by cancer type, but some of the results suggest that dogs, with their extremely sensitive sense of smell, are picking up on something that is being emitted from some of the cancer samples.

Does this mean dogs can reliably sniff out cancer?

Not at all.

This is an interesting field of study that has potential to aid in developing new technologies for cancer detection—the dogs may smell odors that humans can’t detect. These odors might be new biomarkers for a particular cancer, and once they are identified, humans can try to develop technologies that are specific for that biomarker(). However, there is not sufficient data to definitively say that dogs are able to sniff out cancers. Because of this, headlines like the one about Shannen Doherty’s dog are more of an interesting story than a medical finding.

While a few published case studies that sound similar to Shannen Doherty’s story have been published, there is a tendency in academic science to only publish positive results. What this means is that positive things such as a dog sniffing out a cancer are more likely to be published than dogs sniffing at something that is not cancer.

People can look for established signs if they are concerned about breast cancer. Women should be familiar with the look and feel of their breasts, and notice any changes. The Susan G. Komen website notes the following symptoms:

- A lump, hard knot or thickening inside the breast or armpit
- Any swelling, warmth, redness or darkening of the breast

https://www.facingourrisk.org/XRAY/cancer-sniffing-dogs
Any changes in size or shape of the breast
- Any dimpling or puckering of the breast skin
- Itchiness, or a scaly sore or rash on the nipple
- A nipple pulling inwards
- Nipple discharge that suddenly appears
- Any new pains in the breast that don’t go away

While these changes do not indicate that a person has breast cancer, they indicate the need to see a health care provider to get it checked out. Men also get breast cancer, although at far lower rates than women. They may notice similar changes and should take similar action if they do.

Conclusions
Stories about cancer-sniffing dogs are interesting and could lead to some really cool biological discoveries. But they are not clinically applicable for human patients—people can look to their furry friends for companionship, but not for cancer screening.

Posted 9/6/16

References

“Warning Signs of Breast Cancer” from Susan G Komen.
Article: A cancer patient’s tumor is genetically profiled—how does that info help treatment?

SUMMARY

Jessica Wapner’s Scientific American article explores the difficulties of making the vast amount of information acquired from tumor gene tests useful to patients and physicians. (9/20/16). Update: THIS INFORMATION HAS BEEN UPDATED. In late 2017, the FDA approved two separate tumor profiling tests to help guide treatment choices. The FoundationOne CDx (F1CDx) genomic test has been approved to test for 15 different targeted therapies used to treat five types of cancer, including ovarian, colorectal, lung, breast and melanoma. The FDA also approved the MSK-IMPACT and developed for use by Memorial Sloan Kettering Cancer Center (MSKCC) to scan tumor samples for 468 different cancer-associated mutations or alterations.

This article is relevant for:

- People diagnosed with advanced cancer
- Breast cancer survivors
- ER/PR +
- Her2+ breast cancer
Precision medicine is often talked of today in healthcare. President Obama has developed a Precision Medicine Initiative, which aims to “enable a new era of medicine in which researchers, providers and patients work together to develop individualized care.” This individualized care encompasses each person’s unique genes, environment and lifestyle.

This makes a lot of sense—every individual has a different combination of genes, environment and lifestyle. However, where are researchers and healthcare providers in achieving the use of precision medicine for patients? Jessica Wapner’s Scientific American article published in September 2016 explores this topic.

**BRCA mutation carriers are pioneers**

The Scientific American article begins by acknowledging how the discovery of BRCA mutations and the increased risk of breast and ovarian cancer was crucial in emphasizing the role of genetics in treatment decisions. Women who carry a mutation in either BRCA gene can choose to remove their breasts and/or ovaries before they develop any cancer. In 2014, the FDA approved the PARP inhibitor Lynparza, the first therapy that targets cancer in BRCA mutation carriers, for use in some ovarian cancer patients. Ongoing clinical trials are also looking at the use of PARP inhibitors in BRCA mutation carriers with breast and pancreatic cancer. But most cancers are not caused by inherited mutations. So how can genetics help inform treatment decisions in these cases?

**Turning from germline tests to tumor tests**

Researchers understand that all cancers stem from genetic changes. We can think of these changes as two types: germline (inherited mutations), which are present at birth and can be passed down from generation to generation, and acquired or somatic mutations found in tumors that occur and accumulate over the course of a lifetime. It takes more than one mutation for cancer to develop. Most cancers develop as mutations in genes that control cell growth and repair cellular damage accumulate over many years. While certain gene mutations are associated with particular cancers, other mutations vary from tumor to tumor. Because of this, healthcare providers analyze the genetics of patient tumors to catalog the gene mutations so they can see any changes that can be treated by a drug specific for that gene alteration.

Sounds simple, but the problem for patients after they undergo these genetic analyses is that while we can tell a person which mutations are found in her tumor, we may not have a drug to treat it. Researchers have not yet found drugs that target most of these mutations. In fact, there are currently only 29 Federal Drug Administration (FDA) approved tests for mutations that will change what therapies patients can take. As the author notes many patients “learn that their cancers have mutations for which no drug exists.”
The remainder of the article discusses "several obstacles to further progress." However, it focuses mainly on the difficulties of developing therapies that target mutations in patients' tumors. This media article does differentiate between inherited germline mutations and acquired somatic mutations. "For now the gulf between the promise of precision medicine and the reality remains frustratingly large," Wapner writes. One thing that makes it difficult to identify target genetic mutations in patients’ tumors is being able to identify which mutations are important for the cancer, she explains. Researchers also have to figure out which mutations will start causing damage later on. And as if that is not hard enough, researchers have to then successfully develop drugs to target those mutations.

Research is still needed to realize the full potential of precision medicine

This is a paradox of precision medicine. Let’s say that the mutations have been identified and researchers have developed the drugs. The nature of precision medicine revolves around the individual, but in order to determine whether these more unique, individualized drugs are effective and safe, researchers and healthcare providers need a large number of patients to enroll in clinical trials for the drugs. Matching the right patients to the right clinical trials is key to showing that targeted therapies, and the genetic tests that underlie them, are safe and effective.

Precision medicine: present and future

A lot of progress has been made in the cancer genetics world. Various targeted therapies have been developed for HER2-positive breast cancer—Herceptin, Perjeta, Kadcyla and Tykerb all target the HER2 protein. Lynparza, a PARP inhibitor drug that treats advanced ovarian cancer in BRCA mutation carriers by causing BRCA deficient tumor cells to die, is currently in clinical trials to treat breast cancer in BRCA mutation carriers. Tumor genetic tests are also used to help physicians and some breast cancer patients decide whether they need chemotherapy or hormone therapy.

Researchers and healthcare providers have a lot of work to do before precision medicine can be used every day in the clinic. But as Wapner mentioned, certain gene tests are already helping health care providers and their patients make treatment decisions for BRCA-related cancers. Regarding hereditary germline mutations (mutations that children inherit from their parents), patients who do have family histories of cancer and test positive for a cancer risk-increasing gene can benefit from stricter screening regimens. BRCA mutation carriers with breast cancer may also opt for surgeries to remove their breasts and/or ovaries to reduce their risk of a second breast cancer. All of these new technologies allow researchers and healthcare providers to acquire vast amounts of information; information that previous generations could only dream of acquiring—they just need more time to learn how to understand it all.

Posted 9/20/16
Share your thoughts on this XRAY article by taking [our brief survey](https://www.facingourrisk.org/XRAY/tumor-profile-and-treatment).

**References**


[National Institute of Health](https://www.nia.nih.gov/health) Precision Medicine Initiative Cohort Program

American Cancer Society, "[Targeted therapy () for breast cancer](https://www.cancer.org/treatment/understanding-your-treatment/targeted-therapy.html)," September 13, 2016.


**Disclosure**

FORCE receives funding from [industry sponsors](https://www.facingourrisk.org/resources/sponsors), including companies that manufacture cancer drugs, tests and devices. All XRAY articles are written independently of any sponsor and are reviewed by members of our [Scientific Advisory Board](https://www.facingourrisk.org/resources/scientific-advisory-board) prior to publication to assure scientific integrity.

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**Questions to Ask Your Doctor**

- Should I have additional testing on my tumor to guide my treatment?
- Will my insurance pay for additional tumor testing?
- Are there any therapies that we should consider based on my tumor testing?

**Related Resources**

The following organizations have resources related to biomarker testing (tumor testing).

- **FORCE related resources:**
  - Information: [Biomarker tests and cancer treatment](https://www.facingourrisk.org/resources/biomarker-testing)
  - Information: [Common biomarker tests](https://www.facingourrisk.org/resources/biomarker-testing)
  - Information: [DNA () damage repair and cancer treatment](https://www.facingourrisk.org/resources/biomarker-testing) (including information on MMR)
  - Video: [Biomarkers and Liquid Biopsies](https://www.facingourrisk.org/resources/biomarker-testing)
  - XRAY category: [Tumor testing](https://www.facingourrisk.org/resources/tumor-testing)
  - Personalized portal: [Biomarker testing](https://www.facingourrisk.org/resources/biomarker-testing)
  - Cancer Support Community: [Information on biomarker testing](https://www.facingourrisk.org/resources/biomarker-testing)

  **Updated: 01/22/2022**
Study: Do physicians recommend breast cancer screenings based on guidelines?

SUMMARY

Several guidelines help physicians decide when a woman should begin screening for breast cancer and how often she should be screened. However, are these guidelines put into use in the clinic? (8/8/17)

STUDY AT A GLANCE

This study is about:

1. Whether doctors are following recent changes to guidelines for screening mammography for women with no family history of breast cancer or previous breast problems, and
2. Identifying which recommendations doctors are following.

This article is relevant for:

- Women at average risk for breast cancer

This article is also relevant for:

- Women under 45
- Women over 45
- Healthy people with average cancer risk

Be part of XRAY:
**Why is this study important?**

Doctor recommendation has a strong influence on patients’ decisions about cancer screening. However, sometimes doctors’ recommendations do not take into account medical guidelines and patient preferences.

Several different professional guidelines exist for mammograms for women of average risk for breast cancer. Each recommendation differs on:

- Age to begin screening
- Age to end screening
- Frequency of mammograms

The goal of cancer screening is to try to detect cancer earlier, when it is most easy to treat. But cancer screening can come with tradeoffs. False positive results (for example, an abnormal mammogram that turns out not to be cancer), can lead to unnecessary callbacks and/or biopsies that increase stress and anxiety. Overdiagnosis can happen when screening detects a very slow-growing, non-aggressive cancer that might not require treatment.

It is important to know if doctors are following guidelines, and if so, which ones, when making breast cancer screening recommendations to patients. Several guidelines suggest personalized screening for patients. This requires doctors to know their patients’ medical and family health history, educate their patients about benefits and risks of screening, and understand their patients’ individual preferences and tolerance for false positives.

**Study findings:**

Professional societies and organizations do not all agree about when women of average risk for developing breast cancer should begin routine mammogram screening, the frequency of those screenings, and for how long women should continue to be screened. (It is important to note that these recommendations are not for women with increased risk, such as BRCA mutation carriers or those with a family history.)

The researchers surveyed physicians to see how many routinely follow guidelines from one of these organizations:

- The American Cancer Society (ACS):
  - In 2015 the ACS revised their guidelines to recommend personalized screening decisions for women ages 40-44, followed by annual screening starting at age 45, and screening every two years for women ages 55 or older. Women should continue screening as long as they are healthy and have a reasonable life expectancy.

- The US Preventive Services Task Force (USPSTF):
  - In 2016 the USPSTF revised their guidelines to recommend personalized screening decisions for women ages 40-50, followed by mammograms every two years for women ages 50-74.
The American Congress of Obstetricians and Gynecologists (ACOG): In 2011 ACOG published guidelines recommending yearly mammograms for women 40 years or older.

The survey results showed the following:

1. Among doctors who were surveyed:
   - About 81% would recommend screening to women ages 40 to 44.
   - About 88% would recommend screening to women ages 45-49.
   - About 67% would recommend screening in women ages 75 years or older.

2. Doctors reported which guidelines they trusted the most:
   - About 26% trusted ACOG guidelines the most.
   - About 24% trusted ACS guidelines the most.
   - About 23% trusted USPSTF guidelines the most.

3. Differences in doctor recommendations were based on which guideline they trusted most. Doctors who trusted ACS and ACOG guidelines were significantly more likely to recommend screening for younger women compared to those who trusted USPSTF guidelines.

What does this mean for me?

The results of this study are particularly important for average-risk women who are age 40 and above. Screening recommendations are different for patients who have an increased risk of breast cancer due to an inherited mutation in a hereditary breast cancer gene, a strong family history of the disease, a previous breast biopsy demonstrating a high-risk lesion, or a previous diagnosis of breast cancer. Women who are at high risk should be aware of these guidelines. Women should make sure that they share their family history of cancer and other breast cancer risk factors with their doctor.

This study suggests that doctors’ recommendations for women at average risk for cancer vary. This difference may be due to which guideline doctor’s trust most (ACOG, ACS, USPSTF, or other). However, it is not known why doctors trust one guideline more than others. Many guidelines encourage shared decision-making. This means that the doctor and patient decide together which recommendations to follow. Patients should discuss their family history of cancer with their doctors to decide which screening schedule is most appropriate for them.

Posted 8/8/17

Share your thoughts on this XRAYS article by taking our brief survey
The National Comprehensive Cancer Network breast screening guidelines recommend the following for women at average risk for breast cancer:

- **ages 25-39:**
  - practice breast awareness
  - clinical breast exam every 1-3 years
  - risk assessment, including questions about family and personal medical history should be done during clinical exam to find high risk women who may need additional screening

- **ages 40 and older:**
  - practice breast awareness
  - yearly clinical breast exam
  - risk assessment, including questions about family and personal medical history should be done during clinical exam to find high risk women who may need additional screening
  - yearly mammogram - consider 3D mammograms if available.

NCCN has a different set of guidelines for individuals who are determined to be at increased risk for breast cancer.

Many other professional societies and organizations have breast cancer screening guidelines that differ slightly. They don’t all agree on the age mammogram screening should start and how frequently they should be done.

It is important to note, that all the groups support the opportunity for women ages 40 to 49 to decide it mammogram screening is right for them.
WHO COVERED THIS STUDY?

CNN
Doctors still divided on when women should start mammograms

TIME
Most doctors’ breast cancer advice may be out of date

Paste
Despite new guidelines, doctors are still recommending mammograms to women in their 40s

How we rated the media

IN-DEPTH REVIEW OF RESEARCH

Study background:
A number of screening mammography guidelines are available for physicians. Unfortunately, as the authors of this study state, “Different professional societies and organizations continue to disagree over the optimal time to initiate and discontinue breast cancer screening mammography and the optimal screening interval.”

- The American Cancer Society (ACS) 2015 guidelines recommend personalized screening decisions for women 40-44 years old, followed by annual screening starting at 45 years old, and biennial screening for women 55 years or older.
- The US Preventive Services Task Force (USPSTF) 2016 guidelines recommend personalized screening decisions for women ages 40-49, followed by biennial mammograms for women ages 50-74.
- The American Congress of Obstetricians and Gynecologists (ACOG) 2011 guidelines recommend yearly mammograms for women 40 years or older.

This study authors state that physician recommendation is “The most important determinant for patients obtaining screening.” Archana Radhakrishnan, MD and her colleagues from Johns Hopkins University and other institutions surveyed physicians to learn which recommendations they were making to their patients regarding breast cancer screening. Her goal was to see how physicians were incorporating recent guideline recommendations into their clinical practices. Radhakrishnan’s work was published in JAMA Internal Medicine in June 2017.

Researchers of this study wanted to know:
Guidelines outlining the best time to begin breast cancer screening mammography, and how often and how long screening should continue are updated frequently. In addition, different professional societies and organizations that make these recommendations often disagree. The researchers wanted to know whether physicians follow more recent guidelines when making breast cancer screening recommendations for patients who do not have a family history of breast cancer, and which recommendations they trusted the most for their patients.

https://www.facingourrisk.org/XRAY/breast-screening-guidelines
Population(s) looked at in the study:
The physicians involved in the study were part of the Breast Cancer Social Networks study (CanSNET). Surveys were mailed to 2,000 eligible physicians who provided primary care or general gynecologic care to women 40 years or older. After excluding ineligible physicians, the adjusted response rate was 52.3% (871 of 1665). Of these, 871 self-reported their breast cancer screening practices. Physicians were asked whether they typically recommended routine screening mammograms for women with no family history of breast cancer and no prior breast issues, and what recommendations they made to different age groups and at what intervals. They were asked to indicate which organization’s screening guidelines they most trusted. They were not asked whether they practiced individualized decision-making.

Study findings:
This study found that most physicians recommend breast cancer screening beginning at age 40. Of the three guidelines in the survey, this reflects only the ACOG’s recommendation; both the ACS and the USPSTF recommend screening beginning at 45 and 50 respectively. This study suggests that many physicians do not follow the most current of the three guidelines.

- About 81% of physicians would recommend breast cancer screening to women ages 40 to 44.
- About 88% would recommend screening to women 45-49 years old.
- About 67% would recommend screening in women 75 years or older.

Physicians reported which guidelines they trusted the most:

- About 26% most trusted ACOG guidelines.
- About 24% most trusted ACS guidelines.
- About 23% most trusted USPSTF guidelines.

Differences in physician recommendations were based on which guideline they trusted most. Physicians who trusted ACS and ACOG guidelines were significantly more like to recommend screening in younger women compared to those who trusted USPSTF guidelines.

Finally, this study found that gynecologists were more likely to recommend screening for women of all age groups compared to internal medicine physicians and family medicine physicians. This is likely the result of their professional organization, ACOG, recommending annual screening beginning at age 40.

Limitations:
While this study identifies differences in breast cancer screening recommendations among physicians, the researchers did not ask physicians why they favor one guideline over another. However, in an accompanying editorial, “Physician Adherence to Breast Cancer Screening Recommendations” Deborah Grady, MD and Rita F Redberg, MD speculate on why some physicians do not follow evidence-based guidelines, noting:

- medical payment systems in the U.S. more frequently reward ordering tests and procedures than taking the time to talk to patients about the risks and benefits of screening
- physicians’ fears of litigation may result in overuse of screening
- the possibility that physicians over-recommend screening because of decades of media hype, including the long-standing message that early detection must be good and that knowing is better than not knowing.

It is important to note that neither the authors of the study nor the authors of the editorial mention the fact that current National Comprehensive Cancer Network (NCCN) Guidelines also recommend mammograms beginning at
age 40. The NCCN Guidelines, which are updated annually, were not part of the physician survey.

Unfortunately, the study design limits the conclusions that can be drawn about why doctors make certain breast screening recommendations.

**Conclusions:**

This study suggests that not all physicians may follow recent breast cancer screening guidelines. More work needs to be done to understand why this is and how ever-evolving guidelines can be better implemented into clinical practice. Importantly, this study highlights the need for truly informed patient-physician shared decision making. Incorporating evidence and patient preferences into clinical practice and decreasing the influence of non-evidence based factors may ultimately reduce unnecessary screening.

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/breast-screening-guidelines).

Posted 8/8/17

**SEARCH XRAY STUDIES AND ARTICLES**

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**Categories:**

- Alternative Treatments
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- Family & Caregivers
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- Hereditary Cancer
- Intimacy & Body Image

[https://www.facingourrisk.org/XRAY/breast-screening-guidelines](https://www.facingourrisk.org/XRAY/breast-screening-guidelines)
Study: BRCA testing in young women with breast cancer

SUMMARY

National guidelines recommend genetic testing for BRCA mutations in young women who are diagnosed with breast cancer. However, little is known about how women decide to get testing, or how they use genetic information to decide on treatment options. This study found that genetic testing is increasing among young breast cancer survivors, and it explores some of the factors that play into patients’ decision making about genetic testing. (3/22/16)

STUDY AT A GLANCE

This study is about:

How BRCA () testing is used by young women with breast cancer, and how young women make treatment decisions based on genetic information.

Why is this study important?

This article is relevant for:

☑ Young women diagnosed with breast cancer who have not yet had genetic testing

This article is also relevant for:

☑ Breast cancer survivors
☑ ER/PR +
☑ Her2+ breast cancer
☑ Triple negative breast cancer
☑ Women under 45
The National Comprehensive Cancer Network (NCCN) guidelines recommend BRCA testing for women who develop breast cancer at an early age. However, researchers do not know how young women with breast cancer decide to undergo genetic testing and how the results affect their treatment decisions.

**Study findings:**

1. 87% of women diagnosed with breast cancer at or before age 40 reported that BRCA testing was completed within one year after their diagnosis.

2. The number of women with breast cancer at age 40 or younger who had genetic testing increased from about 77% in August 2006 to about 96% in December 2013.

3. About 30% of young women said that genetic information or concern about genetic risk made a difference when they were choosing options for treatment.

**What does this mean for me?**

Knowing that you have a mutation in a BRCA or different breast cancer gene can affect treatment decisions, alert you to other cancer risks (including the risk of a second breast cancer), as well as provide the opportunity to consider additional cancer screening and risk management options. According to the study authors, "Given that knowledge and concern about genetic risk influences surgical decisions and may affect systemic therapy trial eligibility, all young women with breast cancer should be counseled and offered genetic testing, consistent with the National Comprehensive Cancer Network guidelines."

Share your thoughts on this XRAYS article by taking our brief survey.

Posted 3/22/16

**References**


**Disclosure**

FORCEx receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
Study: Breast cancer rates are rapidly increasing among Asian women in California

SUMMARY

The majority of racial groups in the United States have seen declines in breast cancer rates. However, this study provides new insights into the patterns of breast cancer rates in Asian American subgroups in California. Using 26 years of data, this research found that breast cancer is rapidly increasing among this population, contrasting to a decline in rates among non-Hispanic white women in California and nationwide. (8/15/17)
Although other racial groups in the United States have reported declines in breast cancer rates, breast cancer among Asian Americans appears to be increasing, and it is not known why. This pattern of increase is important because it suggests that unexpected public health differences, such as access to screening and care, exist for this population.

**Study findings:**

From 1988 to 2013, 548,259 new cases of breast cancer were diagnosed in women living in California including 383,478 in non-Hispanic Caucasians (NHW) and in 45,721 Asian Americans (AA).

Using this data, this study determined breast cancer rates for Asian American women as a single group and by seven major ethnicities: Chinese, Japanese, Korean, Filipino, Vietnamese, South Asians (Asian Indians and Pakistanis), and Southeast Asians (Cambodians, Laotians, Hmong, and Thai).

- As a single group, Asian American women experienced a rapid increase in breast cancer rates compared to non-Hispanic Caucasian women (NHW breast cancer rates actually declined in California and nationwide during this time).
- Rates increased across all major ethnic groups except Japanese.
- The largest increase was seen in Koreans (1988-2006) and Southeast Asians (1988-2013).
- Among Asian American women younger than age 50, the largest increases occurred in in Vietnamese and other Southeast Asians.
- Among Asian American women over age 50, increases were seen in all AA ethnic groups.

**What does this mean for me?**

This study indicates that breast cancer rates in Asian Americans living in California are rapidly increasing. The results suggest that documenting breast cancer trends for major Asian American ethnic minority groups can contribute to a better understanding why the increase occurred, help target prevention and screening efforts, and guide future research into specific risk factors for each group. These results highlight that there is value and important insight gained when studying distinct ethnicities.

Though more work needs to be done to understand why this increase is happening, as the study authors write, "Culturally tailored efforts to increase awareness of and attention to breast cancer risk factors are needed." Asian Americans should work with their health care provider to determine the best time to start breast cancer screening and the optimal screening schedule. As with all women, it’s important for Asian Americans to know their family history of cancer and speak with a genetics expert if there are any signs of hereditary cancer \(^\text{[1]}\) in their family.

Posted 8/15/17
Share your thoughts on this XRAYS article by taking our brief survey.

**References**

IN-DEPTH REVIEW OF RESEARCH

Study background:
Over the past 15 years, breast cancer rates have either stayed the same or decreased in most US populations. However, rates are increasing in Asian Americans. Scarlett Lin Gomez, PhD, M.P.H. and her colleagues from Stanford Cancer Institute and the Cancer Prevention Institute of California published work in *Breast Cancer Research and Treatment* in July 2017 reporting breast cancer rates in different Asian American ethnicities between 1988 and 2013 in California. This research indicates that to better understand factors that are contributing to increased risk in Asian Americans, it is important to study individually the different Asian ethnicities.

Researchers of this study wanted to:
Better understand what factors may be contributing to the rapid rise in breast cancer rates in Asian Americans.

Population(s) looked at in the study:
The authors studied breast cancer trends by age and stage (I) from seven Asian American ethnic groups in California from 1988 to 2013, and patterns of breast cancer subtypes and age at diagnosis form 2009-2013. Researchers used data from the California Cancer Registry (CCR), which includes four National Cancer Institute Surveillance, Epidemiology and End Results (SEER) databases.

Seven major Asian American ethnicities studied: Chinese, Japanese, Korean, Filipino, Vietnamese, South Asians (Asian Indians and Pakistanis), and Southeast Asians (Cambodians, Laotians, Hmong, Thai). The data from these groups were compared to non-Hispanic whites (NHW).

Study findings:

- Asian Americans as a group experienced a larger increase in breast cancer compared to NHW:
  - Rates increased modestly, while rates for NHW woman fluctuated somewhat from 1998 to 2013.
  - Breast cancer rates increased significantly from 1988 to 2013 for women of Chinese, Filipino, Korean, South...
Asian, Vietnamese, and Southeast Asian descent:

- Rates did not increase for Japanese women during this time.
- The largest rate increase was among Korean and Southeast Asian women between 1988 and 2006.
- Among Asian American women younger than 50 years old breast cancer rates increased for all women except for Japanese, Filipina and South Asians:
  - The largest increases occurred in Korean, Vietnamese, and Southeast Asian women.
- Among Asian American women over age 50, increases were seen in all ethnic groups:
  - Rates among older Japanese women have been generally stable in more recent years.
- Considering stage at diagnosis, increases occurred among all Asian American women for localized and distant stage disease, while rates were stable for regional disease and decreased for unstaged tumors:
  - Rates for distant-stage disease increased most for Filipina women.
- Compared to NHW women, Filipina and Vietnamese women had higher rates of some HER2+ subtypes:
  - Young (under 50) and older (over 50) Filipina women had the highest rates of ER/PR-negative/HER2-positive breast cancer compared to NHW women.
  - The breast cancer rate for the triple-negative breast cancer (TNBC) subtype among all Asian American ethnicities combined was slightly lower compared to NHW:
    - Young South Asian women and older Japanese women, however, had TNBC rates similar to NHW.

**Limitations:**

While this research study confirms what others have observed—that breast cancer rates are increasing in Asian American women—this study has limitations. Because it only included women from California, researchers do not know whether the results can be generalized to Asian American women in other areas of the US. Additionally, there is the possibility of misclassification of ethnicity, though the study authors state that “Misclassification of ethnicity is fairly minimal in cancer registry data.” Furthermore, the number of cases with an unknown breast cancer subtype was high, due mostly to unknown HER2 status. This could have resulted in under-estimation of the rates of different breast cancer subtypes in the Asian American population. Finally, tumor subtyping results may differ because this study combined data that used older methods to subtype breast cancers with newer data that used more advanced techniques. In the past pathologists looked at proteins within the tumor. Newer techniques categorize tumor subtypes based on expression of genes.

**Conclusions:**

This study confirms that breast cancer rates in Asian American women are increasing. More work needs to be done to understand the factors that are contributing to this increase. However, the authors state that “Culturally tailored efforts to increase awareness of and attention to breast cancer risk factors are needed.”

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/breast-cancer-rates-asian-women)
Study: All DCIS is not the same: Young women and African American women at higher risk after DCIS diagnosis

SUMMARY

Diagnoses of ductal carcinoma in situ (DCIS), sometimes called stage 0 breast cancer, have increased in recent decades. Many people with DCIS wonder if they need aggressive treatment. A study looking at the survival of over 100,000 women found that breast cancer mortality after DCIS is low (3%), and identified groups of women who are at higher risk after DCIS. (9/8/15)

This article is relevant for:
- Women diagnosed with DCIS
- Breast cancer survivors
- Women under 45
- Women over 45

STUDY AT A GLANCE

This study is about:

Estimating breast cancer mortality after a DCIS diagnosis and identifying which factors, such as age, ethnicity, and initial treatment received, increase a DCIS patient’s risk of dying from breast cancer.

Why is this study important?

https://www.facingourrisk.org/XRAY/diagnosis-of-DCIS
The study agrees with previous work that shows a low death rate from breast cancer after DCIS diagnosis. The study found a 3.3% risk of death from breast cancer after 20 years beyond a DCIS diagnosis. Finding common factors in women with DCIS who eventually died from breast cancer can help physicians learn who might benefit from more aggressive treatment, which will translate into helping patients and their doctors decide on the best course of treatment.

**Study finding(s):**

1. The risk of dying from breast cancer 20 years after a DCIS diagnosis is low: 3.3% for all women.
2. Women under age 35 at DCIS diagnosis and black women had the highest risk of death from breast cancer after 20 years (approximately 8% and 7%, respectively).
3. Treatment with radiotherapy or mastectomy did not decrease breast cancer mortality.

**What does this mean for me?**

The study showed that the risk of dying from breast cancer after a DCIS diagnosis is generally low, and it opens the possibility of discussing less aggressive treatment alternatives with patients' health care providers. However, the study identified two groups of women with higher breast cancer mortality after DCIS—young women who are diagnosed with breast cancer (under 40 years old) and African American women who are at higher risk of dying from breast cancer. It is important for women in these two groups to discuss DCIS treatment options and heightened surveillance with their health care providers.

Posted 9/8/15

**References**


Esserman L and Yau C. "Editorial: Rethinking the Standard for Ductal Carcinoma In Situ Treatment," JAMA Oncology, Initially published online August 20, 2015.
Article: Report on vaccines to prevent hereditary cancer

SUMMARY

On 05/30/2017, Good Morning America aired a segment entitled “Can a vaccine help prevent breast cancer at its earliest stages?” The story outlines the need for cancer prevention and hints at early research into a cancer vaccine. (8/1/17)

This article is relevant for:

- High risk women who have not had breast cancer
- People with a genetic mutation linked to cancer risk
- Previvors

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people with BRCA mutations. Hager and colleagues hope the vaccine will eliminate cells that are on the way to becoming cancer cells before cancer develops. While the potential vaccine was the focus of the story, Dr. Hager also mentions medications and other trials that could prevent cancer. The reporter states that Hager and his colleagues identified a vaccine that has the “characteristics that will work best against BRCA-related cancers,” and noted that they may be able to begin clinical trials in 2 years.

Preventing cancer is a passion for many in the hereditary cancer community, so this story has led to many questions. It is impossible for a short Good Morning America piece to address all the questions people facing hereditary cancer might have. This XRAYS article addresses some of the questions and issues raised by members of our community about the state of this science.

More research is needed

While the story outlined some very exciting early research, it is important to remember that there are many steps from developing a potential vaccine in the laboratory to having one approved for use in healthy people. FDA approval of a vaccine is the end result of years of discovery and development. This includes: early laboratory research to find vaccine “targets” within abnormal cells that won’t affect healthy cells; creating the vaccine that will bind with these targets; testing the vaccine’s safety and efficacy in animal models, and producing large quantities of the vaccine. Following laboratory research, the vaccine is then tested in humans in clinical trials. Clinical trials in humans are usually conducted in phases, which begin with testing safety and determining the dose that will maximize benefit while minimizing side effects. This phase is followed by larger trials which determine whether or not the vaccine is effective while further evaluating safety.

This process can take many years. One example of this process is the development of human papillomavirus (HPV) vaccines for prevention of cervical cancer. HPV types 16 and 18, the two types responsible for 70% of cervical cancers, were discovered in the early 1980’s. During the 1990’s researchers definitively linked HPV infection to cervical cancer and identified unique HPV targets for HPV vaccines. In 1999 the first HPV vaccine clinical trials began with the first report of efficacy (the vaccine was doing what it was supposed to do—prevent HPV infection) following in 2001. The FDA approved the first HPV vaccine for females in 2006 and for males in 2009—over 20 years after the first early research.

It is unclear from the Good Morning America story how far along this research is. The vaccine research cited in the story has not been published in a peer-reviewed journal, making it difficult for outsiders to evaluate or comment on the status of the research. We will continue to follow this research.
Cancer prevention studies need many participants and many years to complete. People making decisions about cancer risk management now should consult their health care providers about their options in order to decide what is right for them.

**State of cancer vaccine research**

The idea of a vaccine to prevent cancer has been around for many years and the HPV vaccines are a real-world result. Cancer vaccines can be divided into four broad categories:

- vaccines to treat cancer (there is one vaccine approved to treat metastatic prostate cancer)
- vaccines to prevent cancer that has been treated from coming back
- vaccines to prevent cancer-causing viral infections such as the vaccines to prevent cervical cancer (human papilloma virus) and liver cancer (hepatitis B virus).
- vaccines to prevent cancer before it starts

The vaccine discussed in the *Good Morning America* story falls into the fourth category. If it works, it would kill cells that are on the way to becoming cancer cells before cancer develops. **The person who gets the vaccine would then be protected from developing cancer but they would still have the BRCA mutation and could still pass it onto their children.**

While there are currently no vaccines approved to prevent hereditary cancers before they start, recent research into how cancer develops has given researchers clues on how to develop one. One of the challenges in developing vaccines against hereditary cancer is that the cancer develops from the person’s own cells, so the vaccine must be able to tell the difference between a healthy cell and one that is on the way to becoming a cancer cell. This is very different than the HPV vaccine described above, which is more like a traditional vaccine which targets a virus.

**Other BRCA vaccine research**

The *Good Morning America* segment did not cover other groups trying to develop vaccines to prevent BRCA-related cancers. A research group at the Basser Center for BRCA at the University of Pennsylvania led by Robert Vonderheide, MD, PhD and David Weiner, PhD have been studying a new vaccine that could someday prevent BRCA-related cancer in healthy BRCA mutation carriers. They are vaccinating patients with early stage cancers that are at high risk for recurrence in order to understand the safety and immunogenicity (whether the vaccine is reacting to the target molecules) of the vaccine in these patients. While not all patients in this clinical trial are BRCA mutation carriers some are. Once this early study is completed, the goal of the next study would be to vaccinate unaffected BRCA mutation carriers.
carriers to look at safety and immunogenicity in this population. If that looks good the final step would be a large randomized study to look at the risk of developing cancer following vaccination.

FORCE will keep the community updated on results of vaccine trials and other prevention studies for people with BRCA mutations and other genes that increase risk for cancer.

**BRCA affects men too**

The Good Morning America story featured two sisters affected by BRCA mutations talking about their choices for managing cancer risk and their hopes for their young daughters. The story did not mention that men also carry BRCA mutations and can pass the mutation on to their sons or daughters. **Men with mutations in BRCA have an increased risk of male breast cancer, prostate cancer (which usually occurs at younger ages than the general population and can be more aggressive), and pancreatic cancer.** Men with family members who have mutations in BRCA or who have a strong family history of breast or ovarian cancer should consult with a genetics expert to discuss genetic testing. Current strategies to manage cancer risk can be found [here](#).

**Research on prevention depends on clinical trials**

People facing hereditary cancer often want better options for themselves and their families. New forms of screening and prevention require rigorous clinical trials. These trials cannot be completed without mutation carriers who are willing to participate. If you are interested in participating in ongoing trials for cancer screening or prevention, please see our Research section for studies near you.

Posted 8/01/17

Share your thoughts on this XRAY review by taking our brief [survey](#).

**Reference**

Good Morning America. [Can a vaccine help prevent breast cancer at its earliest stages?](#)

**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
Study: New cancer risk estimates for BRCA1/2 mutation carriers

SUMMARY

Cancer risk estimates for BRCA1 and BRCA2 mutation carriers are important because they impact patient decision-making. Until now, almost all risk estimates for mutation carriers were based on results of retrospective studies that looked back on mutation carriers who had cancer. This new study is prospective—it followed almost 10,000 BRCA mutation carriers without cancer to see if or when they developed breast or ovarian cancer. The cancer risk estimates of this study may be more accurate because it followed mutation carriers who did not have cancer over time. (7/28/17)

This article is relevant for:
- Women with an inherited mutation in BRCA1 or BRCA2

This article is also relevant for:
- Previvors
- Triple negative breast cancer
- ER/PR +
- Her2+ breast cancer

STUDY AT A GLANCE

This study is about:

Estimating age-specific risk of breast, ovarian and contralateral breast cancer (breast cancer in the other breast of patients who are already diagnosed with breast cancer) for BRCA1/2 mutation carriers.
Why is this study important?
Accurate cancer risk estimates are especially important for BRCA mutation carriers, because they impact patient medical decision-making. With more accurate cancer risk estimates, health care providers can better advise mutation carriers on when to begin cancer screening or consider risk reduction options.

Previously, most studies that estimated cancer risk for BRCA mutation carriers were retrospective—they developed estimates by looking back at patients who already had cancer. This new study is important because it included a large number of women and is prospective, meaning that it followed BRCA mutation carriers who did not have cancer forward over time. While prospective studies take a very long time, they can provide better risk estimates for use in patient decision-making.

Study findings:
- Among the 9,856 women who had a BRCA mutation:
  - The lifetime breast cancer risk to age 80 was 72% for BRCA1 and 69% for BRCA2.
  - The lifetime ovarian cancer risk to age 80 was 44% for BRCA1 and 17% for BRCA2.
  - The lifetime risk of contralateral breast cancer 20 years after a breast cancer diagnosis was 40% for BRCA1 and 26% for BRCA2.
  - Cancer risks were different depending on family history and where a mutation was located in the BRCA1 or BRCA2 gene.

What does this mean for me?
This study may provide more accurate risk estimates for breast, ovarian and contralateral breast cancer for BRCA1/2 mutation carriers than previous retrospective studies. Because cancer risk estimates are used to help guide the timing of important decisions, these new estimates may change when BRCA mutation carriers consider screening and risk reduction options. This study suggests that cancer risk estimates should be more personalized, and that they can be more precise with consideration of an individual’s unique family cancer history and where the mutation is located in the gene. Together, these results emphasize the importance of genetic counseling for BRCA mutation carriers.

Posted 7/28/17

Share your thoughts on this XRAY review by taking our brief survey.

References
The following organizations have resources related to genetic counseling and testing.

- **FORCE related resources:**
  - Information: [What is genetic testing?](#)
  - Information: [How to get genetic testing](#)
  - Information: [Hereditary cancer, genes and risk](#)
  - Personalized portal: [Genetic testing](#)
  - XRAY category: [Genetic testing](#)
  - Video: [ABC of Cancer Genetics](#)
  - Video playlist: [Genetic testing](#)
  - Blogs: [Genetic testing](#)

- **National Society of Genetic Counseling**
- **JScreen**

Updated: 12/05/2021

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**WHO COVERED THIS STUDY?**

- **Medical News Today**
  - *Breast and ovarian cancers: Large study improves estimates of genetic risk* [Rating: ★★★★☆☆☆]

- **Cancer Research UK**
  - *Study estimates breast and ovarian cancer risk linked to faulty BRCA genes* [Rating: ★★★★☆★☆]

- **Healio**
  - *Researchers define cancer risk in BRCA1/BRCA2 carriers* [Rating: ★★★★☆★☆]

- **Medpage Today**
  - *Study details BRCA carriers' breast ca risk by age* [Rating: ★★★★☆★☆]

- **Medscape**
  - *Most precise estimates ever of cancer risks with BRCA* [Rating: ★★★★☆★☆]

- **WebMD**
  - *When Is risk highest for women with BRCA gene?* [Rating: ★★★★☆★☆]

[How we rated the media](#)
IN-DEPTH REVIEW OF RESEARCH

Study background:
For BRCA mutation carriers, accurate, age-specific cancer risk estimates are important because they affect medical decisions and their timing. Virtually all previous cancer risk estimates for BRCA mutation carriers have been based on retrospective studies. These studies reported breast cancer risk estimates ranging from 40% to 87% for BRCA1 mutation carriers and from 27% to 84% for BRCA2 mutation carriers.

Previous ovarian cancer risk estimates ranged from 16% to 68% for BRCA1 mutation carriers and from 11% to 30% for BRCA2 mutation carriers. The wide range of estimates was likely due to the way the different studies were designed: how families were selected, different characteristics of individual families, how the data were analyzed, and other genetic and lifestyle factors.

Retrospective studies are less likely to produce accurate cancer risk estimates, particularly if an analysis is not adjusted for these factors. On the other hand, prospective studies in which participants are recruited based on their BRCA mutation status and are followed over a long period of time can avoid the limitations associated with retrospective studies. Thus, prospective studies are thought to provide more accurate cancer risk estimates.

For prospective studies, the accuracy of cancer risk estimates depends on both the number of people followed and length of follow-up. The more people followed for substantial periods of time, the more accurate the cancer risk estimates. This prospective study was conducted by Karoline Kuchenbaecker, PhD, of the Centre for Cancer Genetic Epidemiology at the University of Cambridge, England and colleagues.

Researchers of this study wanted to:
- Use data from a large prospective study to estimate age-specific risks of breast, ovarian, and contralateral breast cancer.
- Determine how a family’s cancer history and location of the BRCA1 or 2 mutation in the gene modified an individual’s cancer risk.

Population(s) looked at in the study:
This study only included women with a known BRCA mutations. Women were recruited to participate in this study through several registries: the International BRCA1/2 Carrier Cohort Study (IBCCS), the Breast Cancer Family Registry (BCRF), and the Kathleen Cunningham Foundation Consortium for Research into Familial Breast Cancer (kConFab). The 9,856 study participants were from Europe, Australia, New Zealand, Canada, and the United States. Follow up for all participants was approximately 15 years.

- The breast cancer risk analysis included 3,886 participants (39% of participants). Women were excluded if they were previously diagnosed with breast, ovarian, or other cancer before joining the study; had a risk-reducing bilateral () mastectomy; or did not participate in scheduled follow-ups.

- The ovarian cancer risk analysis included 5,066 participants (51%). Women were excluded if they were previously diagnosed with ovarian or other cancer, had a risk-reducing salpingo-oophorectomy, or did not participate in scheduled follow-ups.

- The contralateral cancer risk analysis included 2,213 participants (22%) Women were excluded if they were previously diagnosed with contralateral breast cancer, ovarian cancer, or other cancer; or did not have a first breast cancer diagnosis at the end of the follow-up period. They were also excluded if they had risk-reducing
bilateral mastectomy or did not participate in scheduled follow-ups.

**Study findings:**

- Of the 3,886 women eligible for the breast cancer risk analysis, 426 were diagnosed with breast cancer during follow-up.
  - Lifetime breast cancer risk estimates to age 80 were:
    - 72% for BRCA1 mutation carriers
    - 69% for BRCA2 mutation carriers
  - Breast cancer diagnoses increased rapidly in early adulthood until ages 30-40 for BRCA1 mutation carriers and until ages 40-50 for BRCA2 mutation carriers. The number of breast cancer diagnoses then remained constant.
- Of the 5,066 women eligible for the ovarian cancer risk analysis, 109 were diagnosed with ovarian cancer during follow-up.
  - Lifetime ovarian cancer risk estimates to age 80 were:
    - 44% for BRCA1 mutation carriers
    - 17% for BRCA2 mutation carriers
- Of the 2,213 women eligible for contralateral breast cancer risk analysis, 245 were diagnosed with contralateral breast cancer during follow-up.
  - Lifetime risk estimates of contralateral breast cancer 20 years after a breast cancer diagnosis were:
    - 40% for BRCA1 mutation carriers
    - 26% for BRCA2 mutation carriers
- Breast cancer risks estimates differed depending on family history.
  - Risk was higher with increasing number of first- and second-degree relatives diagnosed with breast cancer for both BRCA1 and BRCA2 mutation carriers.
  - For women with a BRCA1 mutation and 2 or more first- or second-degree relatives diagnosed with breast cancer, the risk was 73% to age 70 compared to 53% for women with no family history.
  - For women with a BRCA2 mutation and 2 or more first- or second-degree relatives diagnosed with breast cancer, the risk was 65% to age 70 compared to 39% for women with no family history.
- Cancer risks were different depending on the location of a mutation in the BRCA gene. (BRCA1 and BRCA2 mutations were grouped by location: in the beginning, middle, or end of the gene.)
  - BRCA1: Breast cancer risks were higher for mutations located in the beginning (68%) and end (71%) of the gene compared to those in the middle (56%).
  - BRCA2: Breast cancer risks were higher for mutations located in the beginning (69%) and end (67%) compared to those in the middle (51%).
  - The large middle region of the BRCA2 gene was previously described as the "ovarian cancer cluster region"; however, this study found no significant difference in ovarian cancer risk for mutations located in this region.

**Limitations:**

This study had several limitations. Although this study found that cancer risk varied by family history, participants were identified through clinical genetic centers and were more likely to have a family history of cancer. Therefore, the overall cancer risk estimates may not be directly relevant for women who have a BRCA1 or BRCA2 mutation with
no family history of cancer. The results of this study suggest that cancer risks are likely lower for mutation carriers with no family history; however, carriers who have small families, limited knowledge of their families cancer history, few female relatives or female relatives who died young of other causes, or had prophylactic removal of breasts or ovaries should not use these data to assume lower risks. Additionally, because no data (stage, hormone receptor status, etc.) were available on breast and ovarian cancers that developed in study participants, the results represent averages across all tumor types. Furthermore, life time risk estimates were based on a follow-up of 15 years. Actual life time risk may vary for younger participants (i.e. a participant who entered the study at age 30 and was followed to age 45 versus a participant who entered the study at age 60 and was followed to age 75). Finally, this study did not take into consideration the use of chemoprevention strategies (tamoxifen, aromatase inhibitors, etc.) to reduce breast cancer risk or the use of oral contraceptives to reduce ovarian cancer risk.

Conclusions:
For women with a BRCA mutation, the results of this study may provide less biased age-related cancer risk estimates than previous retrospective studies. These results should be used in conjunction with careful genetic counseling and family cancer assessment to guide mutation carriers and their health care providers in clinical decision making. This study demonstrates the importance of knowing your family history and the location of your BRCA mutation because this information may impact individual cancer risk.

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Posted 7/28/17

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Article: Can your breast cancer come back?

SUMMARY

Elaine Howley’s piece for US News & World Report, “Can My Breast Cancer Come Back?” examines a common misperception that many breast cancer patients have after completing treatment, and explains what can actually occur. (7/25/17)

Contents

Are you cured after treatment?

Recurrence, progression and new cancers
Can you reduce your risk for recurrence?
Questions for your doctor

Are you cured after breast cancer treatment?

Women who have breast cancer usually complete one or more treatments, including surgery, radiation or chemotherapy. However, as Howley reports, some patients believe that “they’re done with treatment and can move on” or...
that “finishing chemo means they’re cured.”

Howley interviewed Dr. Melissa Pilewskie, a surgical breast oncologist at Memorial Sloan Kettering Cancer Center, who explained that treatment does not always end with completion of surgery, radiation or chemotherapy. For example, she said that after completing treatment, many women need to take medication for years to help prevent cancer cells from coming back. According to Dr. Maggie DiNome, an associate professor of surgery at the UCLA Breast Center Santa Monica, “Some women with hormone-

diagnosis. After 5 years, recurrence rates decrease somewhat and are more or less constant for the next 25 years. Some breast cancer patients perceive their risk of recurrence is high; therefore, it is important that care providers help these patients better understand their risk.

However, both Drs. DiNome and Pilewskie noted that some women may feel uncomfortable once they complete treatment. Pilewskie explains, “During treatment, most patients feel empowered, that they’re doing something to deal with the disease. But, once that stops, there can be a fear of what happens next…It can be hard emotionally to get back to a healthy lifestyle from that standpoint, and I’ll often refer patients struggling with this for counseling and support groups."

**What’s the difference between recurrence, progression, and a second cancer?**

**Recurrence**

The American Cancer Society states that, “If a cancer is found after treatment, and after a period of time when the cancer couldn’t be detected, it’s called a cancer recurrence.” Patients can experience

- local recurrence (the cancer returns to the same place as where it started)
- regional recurrence (the cancer returns to the lymph nodes close to where it started), and
- distant recurrence (the cancer comes back in a different part of the body).

Howley writes that while there is no official length of time between a patient’s first breast cancer diagnosis and when it returns to qualify as a recurrence, most doctors consider recurrence to be cancer that reappears after you’ve had no signs of it for at least a year.

**Progression**
Progression refers to cancer that has not disappeared, but continues to grow in the body. Some examples of progression include a patient who is initially diagnosed with stage 2 breast cancer but during treatment the cancer grow and progresses to stage 3 breast cancer. Another example may be or a patient who is diagnosed with metastatic disease that does not respond to therapy and grows larger.

**Second cancer**

Sometimes with breast cancer, a new area of cancer can occur in the same or the other breast. When this happens, doctors will run tests to see whether it is recurrent (the original cancer came back) or an entirely new cancer (a second primary or new cancer developed).

The development of a secondary primary breast cancer is much rarer than a cancer recurrence, according to the American Cancer Society. One possible reason for the development of a second primary breast cancer is a patient’s underlying genetics. Patients who have an inherited mutation in a breast cancer susceptibility gene, such as BRCA1 or 2, are at higher risk for developing a secondary primary breast cancer than patients who do not have these mutations.

**Can you reduce your risk of recurrence?**

Howley writes that the lifestyle choices breast cancer patients can make to reduce recurrence are essentially the same as those that initially reduce their risk of developing breast cancer: “Eating right, controlling stress, getting enough sleep, managing your weight, [and] participating in routine screening and exercising.”

Ultimately, while breast cancer can recur, patients should work with their health care providers to determine a schedule for surveillance after treatment and to discuss what they can do to reduce recurrence.

Posted 7/25/17

Share your thoughts on this XRAYS article by taking our brief survey.
Study: Gaps in genetic testing and decision-making for women with early-stage breast cancer

SUMMARY

Genetic testing for cancer risk is now more affordable and easier to obtain. As a result, many breast cancer patients are tested without ever seeing a genetic counselor. Genetic testing results affect treatment decision making, but they can be confusing, especially if patients do not receive genetic counseling. This study looks at breast cancer patients’ experiences following genetic testing and how testing results affect surgical decision making. (7/14/17)
Why is this study important?

Genetic testing for women diagnosed with breast cancer is becoming more common due to decreased costs, improvements in technology, media coverage, public awareness, and the recent introduction of "multi-gene panels" (genetic tests that look for mutations in multiple genes at the same time).

In women diagnosed with breast cancer, genetic testing for a BRCA (1) or other hereditary mutation can affect surgical and treatment decisions. Women who test positive for a mutation in BRCA or other genes are also at higher risk of a second breast cancer or other cancers. Surgeons often recommend "bilateral (I) mastectomy" (removal of both breasts) for women who test positive for a gene mutation. On the other hand, previous research shows that bilateral mastectomy does not increase survival for average-risk women. For this reason, most surgeons recommend "breast conserving surgery" (also known as lumpectomy (1)) for treatment of breast cancer in women who do not carry a gene mutation and are not considered at high risk for further cancer.

Genetic tests are complicated and the results are not always a straightforward positive or negative. Some test results may come back as a Variant of Uncertain Significance (1) or VUS (1). These results are considered by experts as "inconclusive" test results. Breast cancer patients with inconclusive genetic test results may not be at increased risk for further cancer and may not benefit from bilateral mastectomy.

This study looks at experiences and views of genetic testing in patients who were newly diagnosed with breast cancer. It also looks at views and attitudes of the patients’ surgeons with respect to genetic counseling, testing, and how genetic testing results affect treatment decisions.

Study findings:

1. Of the 666 women who reported they had genetic testing:
   - Approximately half discussed their results with a genetic counselor.
   - 80% of women who had a mutation in BRCA1 (1), 2 or another gene that increased cancer risk decided to have a bilateral mastectomy.
   - 51% of women who had a variant of uncertain significance (VUS) in a gene that increased cancer risk had a bilateral (double) mastectomy.

2. Surgeons’ confidence in talking about genetic testing increased as they treated more patients.

3. 24% of surgeons who saw more breast cancer patients reported that they recommended the same treatment (bilateral mastectomy) for
women who had a VUS as for patients who had a pathogenic BRCA mutation.

4. 50% of surgeons who saw fewer breast cancer patients treated patients with a VUS the same as they treated patients with a pathogenic BRCA mutation

**What does this mean for me?**

This study shows that genetic testing can help breast cancer patients make treatment decisions.

National guidelines recommend that patients meet with an expert in cancer genetics who can interpret the test results and explain what the results mean for patients and their families.

Despite the guidelines, not all patients who undergo genetic testing receive genetic counseling before and after genetic testing. Without genetic counseling, experts are concerned that breast cancer patients may not receive all the information that they need to make informed decisions about their surgery or treatment. This study reinforced that concern. Surgeons with less experience were more likely than more experienced surgeons to recommend double mastectomy to women with inconclusive genetic test results. Additionally, many of the women who had an inconclusive genetic test result underwent bilateral mastectomy. Experts are concerned these women may have chosen double mastectomy because they were not fully informed about the meaning of their test results. According to the study authors, “Half of average-risk patients with a VUS undergo BLM (bilateral mastectomy), suggesting a limited understanding of these results. These findings emphasize the need to address challenges in personalized communication about genetic testing.”

Despite this concern, there are many valid reasons why women with negative or inconclusive genetic test results choose double mastectomy after breast cancer.

Patients who receive genetic testing should discuss their results with a genetics professional to help them with treatment decisions. The role of a genetic counselor is to educate patients about genetic testing, provide information on their treatment and prevention options, and help them make informed decisions about their medical care. It is important that patients receive balanced and up-to-date information in order to make an informed decision in consultation with their health care team.

Share your thoughts on this XRAY review by taking our brief survey.

Posted 7/14/17

**References**

Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
The following organizations have resources related to genetic counseling and testing.

- FORCE related resources:
  - Information: [What is genetic testing?](#)
  - Information: [How to get genetic testing](#)
  - Information: [Hereditary cancer, genes and risk](#)
  - Personalized portal: [Genetic testing](#)
  - XRAY category: [Genetic testing](#)
  - Video: [ABC of Cancer Genetics](#)
  - Video playlist: [Genetic testing](#)
  - Blogs: [Genetic testing](#)
  - [National Society of Genetic Counseling](#)
  - [JScreen](#)

Updated: 12/05/2021

WHO COVERED THIS STUDY?

**US News**
Also published in:
The same article was also covered by [Health Day](#)

[Misunderstood gene tests may lead to unnecessary mastectomies](#) ★★★★☆

**Medical Daily**

[Breast cancer prevention: patients with uncertain genetic tests may get unnecessary double mastectomies](#) ★

★★★★☆

**Crime Online**

[Stunning allegation: Half of all mastectomy patients do NOT have cancer gene: Misreading data?](#) ★★★

How we rated the media

[In-Depth](#) (click to expand)
IN-DEPTH REVIEW OF RESEARCH

Study background:

Genetic testing is becoming more common for breast cancer patients, helping patients and providers make decisions about treatment and surgery. National guidelines recommend that patients see experts known as genetic counselors before and after genetic testing. However, experts are concerned that there are not enough genetics experts to meet the growing need.

Allison Kurian, MD and colleagues from Stanford University School of Medicine and other institutions published work in the Journal of Clinical Oncology that examines how genetic testing results affect treatment decisions for patients with early-stage breast cancer. They also surveyed surgeons on their recommendations for mastectomy versus lumpectomy based on their patients’ genetic test results.

As the research study authors write, “The genetic counselor workforce is insufficient to meet the growing demand for timely incorporation of genetic testing into treatment decisions.” Because of this, healthcare providers such as surgeons, medical oncologists and other physicians may feel that they need to counsel patients about their genetic testing results, which may be difficult for some healthcare providers who have limited experience with genetic testing.

Researchers of this study wanted to know:

How genetic testing results affect surgical and treatment recommendations and decisions for women who have been diagnosed with early-stage breast cancer.

Population(s) looked at in the study:

The 666 women involved in this study were identified by Surveillance, Epidemiology, and End Results (SEER) registries from Georgia and Los Angeles County. These women were between 20 and 79 years old, were diagnosed between 2014 and 2015 with stage I–II breast cancer, and reported that they already had genetic testing. The study included 57% non-Hispanic whites, 18% blacks, 14% Hispanics and 9% Asians.

Providers who ordered genetic testing for the patients in this study included surgeons, medical oncologists, and genetic counselors. Patients reported talking about their genetic test results with surgeons only, medical oncologists only, genetic counselors only, or multiple health professionals.

Two months after their breast cancer surgeries, patients answered a questionnaire that included questions regarding genetic testing, whether they discussed their genetic testing results with a health care professional or genetic counseling expert, when they received their results, the genetic testing result, who ordered the genetic test, surgical procedures, and race.

Surgeons were also surveyed. They responded about the number of new patients with breast cancer they treated in the past year and their confidence in discussing the pros and cons of genetic testing with their patients. Regarding patients who were candidates for genetic testing, surgeons were asked how often they referred women for genetic counseling ordered testing without a referral for genetic counseling, and delayed surgery until test results were obtained. Surgeons were also asked whether they would offer breast-conserving treatment as a reasonable option for someone with a BRCA1 or 2 mutation or if they would manage a patient with a VUS in the same way they would manage a BRCA mutation carrier.

Study findings:
Of the 666 women who participated in this study, 53 had a mutation in BRCA1, BRCA2, or other gene known to increase cancer risk; 59 had a variant of uncertain significance (VUS); and 463 had no mutation (pathogenic or VUS) in any of the genes tested. The remainder of the 666 women did not report their genetic testing result.

- Approximately half of the 666 women who reported genetic testing talked with a genetic counselor about their results.
- 80% of the women who had a mutation in a gene known to increase cancer risk decided to have a bilateral mastectomy.
- 51% of the women who had a VUS in a gene known to increase cancer risk decided to have a bilateral mastectomy.
- 16% of patients with no mutation and no VUS decided to have a bilateral mastectomy.

337 (the overall response rate was 78%) surgeons were surveyed. Of these, 98 (29%) indicated that they saw a high volume of breast cancer patients (51 or more treated in the past year). 128 (38%) indicated that they saw a low volume of breast cancer patients (0 to 20 treated in the past year). 101 (30%) indicated that they saw a moderate number of patients while 10 (3%) did not report on number of breast cancer patients seen.

- About one-fourth of surgeons who saw a high volume of new breast cancer patients managed women with a VUS as though they had a deleterious mutation.
- About half of surgeons who saw a low volume of new breast cancer patients managed women with VUS as though they had a deleterious mutation.

Limitations:
The patient survey data used in this study may include inaccuracies due to errors in recall. Patient medical records were not reviewed to validate how well they remembered details about their situation or care. The study did not look at other reasons why patients may have chosen double mastectomy or the degree that they were involved in the decision-making process. Additionally, while the study began with 666 women, only a relatively small sample size, 53 carried a deleterious mutation, and only 59 had a VUS. Because the study was conducted in Los Angeles and Georgia, the results may not apply to other areas in the United States.

Conclusions:
Previous research indicated that bilateral mastectomy does not increase survival for average-risk women. For this reason, most surgeons recommend lumpectomy for treatment of breast cancer in women who do not carry a gene mutation and are not considered at high risk for further cancer. However, bilateral mastectomy does reduce the risk of a second breast cancer diagnosis. This is particularly relevant for women who carry a mutation in BRCA1/2 or another gene that increases breast cancer risk. The study authors write that, “It is essential that patients understand the meaning of their results and that [bilateral mastectomy] be discussed with mutation carriers but not recommended for women with negative or VUS results.” This study suggests that a substantial number of women with early-stage breast cancer who have genetic testing and carry a VUS are having bilateral mastectomy.

Additionally, some surgeons are treating their breast cancer patients who carry a VUS as though they carry a deleterious mutation that is known to increase cancer risk. While each patient should have a personalized care and treatment plan that is best for them, patients should make sure that they discuss their genetic testing results with a genetics professional. The results of this research highlight the challenge of including rapidly advancing genetic testing technology into personalized breast cancer treatment.

Posted 7/14/17
Study: Diet during teen years and early adulthood is linked to breast cancer risk

**SUMMARY**

During teen years, breast tissue grows rapidly in young girls and is more likely to be harmed by substances that are known to cause cancer. Few studies have looked at the relationship between diet during puberty and breast cancer risk. This study looks at how a woman’s diet during their teenage years and early adulthood is associated with breast cancer development later in life. (6/30/17)

This article is relevant for:

- Adolescent and young adult women
- Healthy people with average cancer risk
- Women under 45

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https://www.facingourrisk.org/XRAY/teenage-diet-and-risk
The research in this study suggests that teenagers and young women with “inflammatory diets” (i.e. diets high in sugar, refined grains, and red meat and low in green leafy vegetables) have an increased risk of developing breast cancer before age 50. While this research is not as relevant for all adult women, it is important for young women and parents of teenage girls who may be concerned about their breast cancer risk.

Study findings:
The study authors looked at the influence on breast cancer of an inflammatory diet, which largely consists of foods that trigger an inflammation response in the body. These foods include sugary foods, diet soft drinks, refined grains (white bread, pasta, bagels, etc.), red and processed meat, margarine, corn, certain other types of vegetables (celery, mushrooms, green peppers, eggplant, and summer squash), and fish (tuna, mackerel, salmon, sardines, bluefish, swordfish) and lower intake of green leafy vegetables (spinach, lettuce), yellow vegetables (carrots, yellow/winter squash, yams), cruciferous vegetables (broccoli, Brussels sprouts, cauliflower, kale, greens, cabbage), and coffee.

Among the 45,204 women participating, the increased risk of premenopausal breast cancer was:

- 35% in women whose diet patterns during adolescence was classified as inflammatory.
- 40% in women whose diet patterns during early adulthood was classified as inflammatory.

Exactly how an inflammatory diet in adolescence and early adulthood impacts risk of premenopausal breast cancer is unclear; however, these results support other studies that show a risk between chronic inflammation and other types of cancers.

What does this mean for me?
The results presented in this study are important because very little is known about how an adolescent diet contributes to breast cancer risk in adults. Because we are beginning to understand that breast cancer may begin much earlier than previously thought, taking years or even decades to develop, it is important to encourage young girls and teenagers to eat healthier. Dr. Karin Michels of the University of California Los Angeles who helped lead this study said, “Eating a healthier diet later in life does not seem to help as much as starting out eating well.”

Posted 6/30/17

Share your thoughts on this XRAY review by taking our brief survey.

References
The American Cancer Society (ACS) guidelines on exercise, nutrition and weight for cancer prevention recommend the following:

**Diet and nutrition**

- Follow a healthy eating pattern, which includes:
  - foods that are high in nutrients in amounts that help you get to and stay at a healthy body weight.
  - a variety of vegetables, fiber-rich legumes (beans and peas), and whole fruits in a variety of colors. ACS recommends people consume at least 2½ to 3 cups of vegetables and 1½ to 2 cups of fruit each day, depending on your calorie requirements.
  - whole grains rather than refined grains. ACS recommends that at least ½ of your grain consumption consists of whole grains.
- A healthy eating pattern limits or does not include:
  - red and processed meats.
  - sugar-sweetened beverages.
  - highly processed foods and refined grain products.
- It is best not to drink alcohol. People who do choose to drink alcohol should:
  - have no more than 1 drink per day for women or 2 drinks per day for men.

**Exercise**

- Exercise regularly.
  - Adults should get at least 150 minutes of moderate-intensity activity (equal to a brisk walk) or 75 minutes of vigorous activity (makes your heartbeat and breathing faster and makes you sweat) each week, preferably spread throughout the week.
  - Physical activity has been shown to lower the risk of several types of cancer, including breast, endometrial, prostate (1) and colon cancer. It also reduces the risk of other serious diseases such as diabetes and heart disease.
WHO COVERED THIS STUDY?

HealthDay
Bad diet in youth might raise risk of early breast cancer

NBC News
Bad diet in teen years could raise later breast cancer risk

Fox News
How your teen's diet could affect her breast cancer risk

CBS SF Bay Area
Study links junk food diet during adolescence, early adulthood with premenopausal breast cancer

How we rated the media

IN-DEPTH REVIEW OF RESEARCH

Study background:
Although the effect of adult diet on cancer risk has been well studied, statistical models and animal studies suggest that the years before a woman has her first child are critical when trying to estimate breast cancer risk. This study specifically looks at how a woman’s diet during her teenage years and early adulthood affects breast cancer risk.

Researchers of this study wanted to know:
How a woman’s diet during her teenage years and young adulthood affects her risk of breast cancer later in life.

Population(s) looked at in the study:
Holly R. Harris and colleagues used data from the Nurses’ Health Study, which began in 1989. At the beginning of the study 116,430 nurses participated by filling out a questionnaire on their lifestyle and medical history. Eight years later, 47,355 participants (who were 33 to 52 years old the time) completed a second questionnaire about their diet during high school. Women were excluded from the analysis if their reported daily caloric intake was less than 500 calories or greater than 5,000 calories, if they left more than 20 questions unanswered, if they did not report their height, or if they were diagnosed with any cancer except melanoma.

Adolescent diet was measured by asking the participants which of 124 food items they ate, including foods that were commonly eaten from 1960 to 1980 when they would have been in high school. These women first reported their adult diets in 1991, when they were 27 to 44 years old. That survey included 130 food items and was completed every 4 years. For both adolescent and adult surveys, participants were asked how often, on average, they had eaten each food item, ranging from "never" to "6 or more times a day."
Every other year, participants were asked if they had been diagnosed with breast cancer in the previous 2 years. They were considered premenopausal if they still had periods, or had at least one ovary remaining if they were 48 years old or older. Women were considered postmenopausal if they reported being so due to natural menopause or bilateral oophorectomy.

The inflammatory diet pattern was previously identified in other studies; researchers looked at the levels of biomarkers of inflammation (certain molecules known to be elevated during an inflammatory response) in participants’ blood. They then compared biomarker levels to the food items the participants ate.

Researchers in this study analyzed diets and breast cancer in three categories: adolescent (ages 13 to 18), early adulthood (ages 27 to 44), and combined diets (adolescent and early adulthood). They also looked at other variables. Adolescent variables included age, total adolescent calories, height at age 18, age at which their periods began, body mass index, and adolescent physical activity. These same variables were included for adult women. Premenopausal women were also asked about age at first childbirth, number of children delivered, oral contraceptive use, adult physical activity, alcohol consumption, weight change since age 18, and history of benign breast disease. Postmenopausal adult variables included age at menopause and hormone usage.

**Study findings:**

Among the 45,204 study participants, 1,477 cases of breast cancer were reported over the 22-year follow-up: 870 premenopausal cases and 490 postmenopausal cases.

- Women who consumed an inflammatory diet during adolescence:
  - had a higher Body Mass Index (BMI) at age 18
  - were less physically active in adulthood
  - gained more weight since age 18
  - were more likely to have used oral contraceptives
  - ate an average 3.3 servings of refined grains and 1.2 servings of red meat a day

- Women whose diet was low in inflammatory foods:
  - ate 1.5 servings of refined grains and 0.6 servings of red meat a day
  - on average, these women also ate 0.7 servings a day of leafy vegetables compared to 0.3 servings for women whose diet pattern included inflammatory food

**The most significant finding was:**

- Women who remembered having eaten a very highly inflammatory diet as teens were 35% more likely to develop premenopausal breast cancer than women who ate the least inflammatory diet.
- Women who remembered having eaten a very highly inflammatory diet as young adults were 40% more likely to develop premenopausal breast cancer than women who ate the least inflammatory diet.

Among all participants, an adolescent inflammatory diet was associated with premenopausal breast cancer, and among all foods eaten, adolescent intake of processed meats was the food type most strongly associated with this risk. No association was made with an adolescent inflammatory diet and overall or postmenopausal breast cancer.

**Limitations:**

Few studies on adolescent diet and breast cancer have been conducted because of the difficulty in accurately reporting diet during this time. To accurately collect this data researchers would have to randomly assign large numbers of teenagers to eat different diets and then follow them for over 20 years. Among the few studies reported,
eating higher amounts of soy and fiber during adolescence has been linked to reduced breast cancer risk, while eating red meat during adolescence has been shown to increase the risk of premenopausal breast cancer. More research is needed to confirm the results presented in this study.

Researchers did have not have participants’ adolescent biomarker levels. If foods eaten during adolescence influence biomarkers levels differently than they do in adults, this would not be detected in this study. Other limitations were that participants self-reported dietary information, and they were 33 to 52 years old when they were asked to remember their diets decades before, during high school. While recalling one’s adolescent diet has been shown to be reasonable, some reporting error is likely. It is also possible that teens who ate more nutritiously during adolescence had other lifelong healthy habits which were not taken into account.

Conclusions:

In summary, this new report suggests that women who ate an inflammatory diet during adolescence and early adulthood were at increased risk of premenopausal breast cancer. The results of this study are important because very little is known about how adolescent diet contributes to risk of premenopausal breast cancer. Eating less refined flour, sugar, and red meat and eating more vegetables provides many healthful benefits, and this study shows that doing so early in life can impact the risk of premenopausal breast cancer. “A healthy lifestyle early on is much, much more important than we appreciated,” Michels said. “Now we have to communicate this to girls.”

Posted 6/30/17
Article: FDA busts myths of preventing and treating cancer by eating apricot kernels, herbs, and other ingredients

SUMMARY

Maggie Fox (NBC News) writes about a new FDA report that warns of 14 "fraudulent" cancer products claiming to either cure or treat cancer (1). The companies that sell these products claim that many of them also prevent cancer, but are they safe or effective? (6/26/17)

WARNINGS AT A GLANCE

The United States Food and Drug Administration (FDA) sent warning letters to 14 fraudulent cancer cure companies. Apricot kernels, herbs and other ingredients are the focus of Maggie Fox’s NBC News coverage of the FDA actions.

This article is relevant for:

- People diagnosed with or concerned about their risk for cancer
- Breast cancer survivors
- Metastatic cancer
- Ovarian cancer survivors
- People with a genetic mutation linked to cancer risk

This article is also relevant for:

- Hereditary cancer
- Genetic testing
- Risk management and treatment
- Research and clinical trials
- Privacy, policy, and legal issues
- Support
- Education
A cancer diagnosis of an individual, family member or friend is challenging and can cause extreme distress; people diagnosed with cancer may be desperate to try anything and vulnerable to these companies’ claims to “cure” or “treat” cancer. The companies making these inaccurate are a danger and represent an injustice to the people they claim to help.

FALSE CLAIM: “If a person eats 6-12 apricot kernels per day, they will never have to worry about cancer.”

This false claim is advertised on one of the companies’ websites. Cancer patients and their families may be vulnerable and more willing to put skepticism aside if they hear or read that something can cure cancer. But these companies go further than that. According to a blog post written by the FDA’s Donald Ashley, JD and Douglas Stearn, JD, "These companies use slick ads, videos, and other sophisticated marketing techniques, including testimonials about miraculous outcomes. Often a single product was promoted as a treatment or cure for multiple diseases in humans and animals (2).”

However, these products have not been FDA tested. Claims that they cure or treat cancer are fake, and they are potentially dangerous. As Maggie Fox writes, “...‘Everything Herbs’ was advertising apricot kernels, which contain deadly cyanide. Apricot seeds were the basis for amygdalin (laetrile), an unproven but popular “alternative” cancer therapy sold online and in overseas clinics since the 1970s, despite much evidence it is worthless.”

The FDA issued warning letters to 14 companies regarding their fraudulent claims about their products: AIE Pharmaceuticals, Inc.; Amazing Sour Sop, Inc.; BioStar Technology International, LLC; Caudill Seed & Warehouse Inc.; DoctorVicks.com; Everything Herbs; Hawk Dok Natural Salve, LLC; Healing Within Products & Services, Inc.; LifeVantage Corporation; Nature’s Treasure, Inc.; Oxygen Health Systems, LLC; Sunstone, Inc.; The Vibrant Health Store, LLC (dba Dr. Christopher’s Herbs); and The Vitamin C Foundation (3).

What does this mean for me?

The FDA is responsible for “Protecting the public health by assuring the safety, effectiveness, quality, and security of human and veterinary drugs, vaccines and other biological products, and medical devices.” Drug companies seeking FDA approval to sell a new drug are required to test it in many ways, from early experiments done a laboratory to seeing if the drug is safe and effective for use in humans.

Additionally, clinical guidelines have not been written for any of these products. As defined by the Institute of Medicine, clinical guidelines are “…systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances (4).” These guidelines are made after enough high-quality research studies are completed that support the use of the products in question. For example,
many researchers and physicians from different academic institutions would have agree that eating 6-12 apricot kernels a day would prevent cancer for the guidelines to incorporate this practice.

Being diagnosed with cancer or experiencing a loved one going through cancer is difficult, and it is inappropriate, illegal and unethical for companies to promote products that have not been proven to be safe or effective. But because companies like these exist, cancer patients and their loved ones should be sure to confirm that the products or treatments they hear and read about are critically examined by trusted resources, such as the FDA and a person’s own health care providers.

Share your thoughts on this XRAYS article by taking our brief survey

References
Fox M. “FDA Warns of 14 ‘Fraudulent’ Cancer Cure Companies.” NBC News. Published online first on April 25, 2017.

Ashley DD and Stearn D. “FDA Takes Action Against Fraudulent Cancer Products.” U.S. Food & Drug Administration. Published online first on April 25, 2017.

FDA: Illegally Sold Cancer Treatments

Disclosure
FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
Study: Cost savings associated with a shorter course or omission of radiation treatment for early-stage breast cancer

SUMMARY

Breast cancer treatment costs are high. Lumpectomy followed by radiation therapy is a common treatment for early-stage breast cancer; however, patients may receive different radiation regimens, which carry different costs. Authors of this research study wanted to estimate the potential health care cost savings if early-stage breast cancer patients received the least expensive radiation regimen for which they were safely eligible. (6/20/17)
Why is this study important?

According to the study authors, "Breast cancer treatment costs are the highest among all cancer types, estimated to reach $20 billion by 2020." While patients and their healthcare providers should work together to determine the most effective treatment plan, high-quality cost-effective treatments are increasingly needed.

For patients with early-stage breast cancer, who do not carry a BRCA, PALB2, ATM, CHEK2 or other genetic mutation associated with increased breast cancer risk, lumpectomy is often the preferred surgical treatment option. Lumpectomy is often followed by radiation therapy (RT), a type of cancer treatment that uses beams of energy to kill cancer cells. Whole breast irradiation (WBI) is recommended for most women after lumpectomy as it has been shown to reduce local recurrence and improve overall survival. Currently there are two standard-of-care radiation therapy regimens following lumpectomy.

- Conventional Whole Breast Irradiation (C-WBI), consists of 5 to 7 weeks of daily radiation treatments.
- Hypofractionated WBI (HF-WBI) involves delivering a higher dose of radiation over a shorter period of time of about 3 weeks.

HF-WBI is considered less costly than C-WBI. As recently as 2014, patients were commonly treated with the conventional 5-7 week radiation therapy. However, several randomized trials have confirmed that patients treated with the shorter, HF-WBI have similar disease-free and overall survival rates as those treated with CF-WBI. The American Society for Radiation Oncology (ASTRO) and other professional groups have issued guidelines for use of HF-WBI in patients: women with small (≤3 cm), node-negative breast cancers with negative surgical margins, patients who are at least 50 years old, and patients who have non-invasive disease.

Study findings:

1. About 57% of early-stage breast cancer patients in 2011 were safely eligible for a shorter radiation treatment or no radiation treatment compared to the radiation treatment that they received.

2. The study authors estimated that if these breast cancer patients had received the least expensive radiation treatment for which they were safely eligible, estimated savings would have been almost $170 million.

What does this mean for me?

This study received a “Medium” relevance score because the results do not necessarily impact the medical decisions of women diagnosed with breast cancer today.
The research presented suggests that costs for radiation therapy to treat early-stage breast cancer in 2011 would have been significantly less if patients would have received the least expensive radiation regimen for which they were safely eligible. The authors concluded that, “A majority of women in the United States are receiving longer and more costly adjuvant radiation treatment than current data deem medically necessary.”

While this study is interesting, even the authors noted that treatment decisions are complex and based on many factors that were not considered in this study. It is possible that the women who looked like they were eligible for less radiation on paper actually needed a higher dose based on their specific anatomy or other factors found on physical exam. Finally, this study looked at patient data from 2011. When considering RT patients should discuss with their health care provider current recommendations. Careful consideration of a radiation treatment regimen must be made by a patient and her care team.

Posted 6/20/17

Share your thoughts on this XRAYS article by taking our brief survey

References


Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

Questions to Ask Your Doctor

- Do I need radiation treatment?
- What are my radiation treatment options?
- How do I decide which radiation treatment is best for me?
WHO COVERED THIS STUDY?

CBS News
Are some breast cancer patients getting too much radiation?

Healio
Shorter radiation could safely lower costs of breast cancer treatment

Medscape
Safe way to save $164 million a year in breast cancer

How we rated the media

IN-DEPTH (click to expand)

SEARCH XRAY STUDIES AND ARTICLES

Keyword:  
Cancer Type:

Choose

Relevant for:

Choose Cancer Type First...

Categories:

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing

https://www.facingourrisk.org/XRAY/cost-savings-with-shorter-radiation
Study: Does working night shifts increase breast cancer risk?

SUMMARY

The World Health Organization’s International Agency for Research on Cancer (IARC) classified night shift work as a possible risk factor for breast cancer in 2007, although the majority of the evidence for this claim came from studies of animals after their normal sleep-wake cycle was disrupted. The authors of this study surveyed women from three different cohorts to examine whether night shift work can increase a woman’s breast cancer risk. (3/24/17)

This article is relevant for:
- Women who work night shifts or have in the past
- Healthy people with average cancer risk
- People with a genetic mutation linked to cancer risk
- Women under 45
- Women over 45
In 2007, the World Health Organization’s International Agency for Research on Cancer (IARC) classified night shift work as a breast cancer risk factor. However, most of the evidence used to make this statement was based on research studies of animals after their normal sleep-wake cycle (circadian rhythm) was disrupted. As many women work night shifts for their occupation, it is important to understand whether this is a risk factor for breast cancer development in humans.

**Study findings:**

1. Women who worked night shifts had the same rate of breast cancer as women who did not.
   - Even women who worked night shifts for 20 or more years did not have an increased risk of developing breast cancer compared to women who had never worked night shifts.

**What does this mean for me?**

For some women, night shift work is unavoidable and even preferred. This study suggests that it does not significantly increase a woman’s risk of developing breast cancer—women who worked night shifts were no more likely to develop breast cancer than women who didn’t. Because this study looked at all women, it is not known how night shift work affects women who are already at high risk for breast cancer. All women, regardless of whether or not they do night shift work, should strive to live a healthy lifestyle that includes regular exercise, limited alcohol intake, and a nutritionally balanced diet, as these actions generally lower cancer risk.

Posted 3/24/17

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/night-shift).

**References**


**Disclosure**

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WHO COVERED THIS STUDY?

Medical News Today
Night shift work ‘does not raise breast cancer risk,’ study finds

BBC
Breast cancer risk ‘not increased’ by night shifts

Daily Mail UK
Working night shifts does NOT raise the risk of breast cancer: Women who do shifts are ‘no more likely to get the disease than anyone else’

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
The World Health Organization’s International Agency for Research on Cancer (IARC) released a statement in 2007 saying that “Shift work that involves circadian disruption is a probable (breast) carcinogen." In other words, night shift work that requires women to work when they would normally sleep increases breast cancer risk. However, the statement was primarily based on studies that looked at animals after their normal sleep-wake pattern (circadian rhythm) was disrupted, with minimal evidence from human studies.

Ruth Travis and colleagues from the University of Oxford and other institutions published work in the Journal of the National Cancer Institute in October 2016 regarding whether night shift work increases breast cancer risk in women.

Researchers of this study wanted to know:
Does working night shifts increase a woman’s breast cancer risk?

Population(s) looked at in the study:
The study authors collected data from the following three cohorts:

- The Million Women Study surveyed 522,246 women.
Participants were asked whether they had ever regularly worked at night or on night shifts. The women who answered "yes" were asked about how long they worked night shifts and the nature of their work.

The UK Biobank cohort surveyed 251,045 women.

Participants were asked about their employment; women who were employed were asked if they worked night shifts either "never/rarely," "sometimes," "usually," or "always."

The EPIC-Oxford cohort surveyed 22,559 women.

Participants were asked whether they had ever regularly worked at night or on night shifts. The women who answered "yes" were asked about how long they worked night shifts and the nature of their work.

Women who had invasive cancer of any type or in situ breast cancer (DCIS or LCIS) before they began working night shifts were not included in this study.

**Study findings:**

1. Women who worked night shifts had the same rate of breast cancer as women who did not.
   - Even women who worked night shifts for 20 or more years did not have an increased risk of developing breast cancer compared to women who had never worked night shifts.

2. Additionally, the authors also pooled the data from 10 past studies done by different researchers. Here they also saw no difference in breast cancer rates between women who worked night shifts and those who did not.

**Limitations:**

Although the study included many women, relatively few (1,000) reported working night shifts long term. The study authors recognize that small increases in breast cancer risk for women who worked night shifts long term cannot be ruled out because of this small sample size. Additionally, other differences were observed between women who worked night shifts and those who did not: women who worked night shifts were slightly more likely to be obese, smoke, and to take medications to help them sleep. Finally, the meta-analysis portion of the research study where the researchers pooled information from past studies only included retrospective studies, meaning that the researchers of the studies used for this analysis did not collect their own data, and so they could not control for all factors.

**Conclusions:**

This study suggests that night shift work does not increase a woman's risk of breast cancer. While more work should be done to confirm these findings, women who are concerned about their breast cancer risk should talk to their health care providers.

Posted 3/24/17

Share your thoughts on this XRAYS article by taking our brief survey.

**SEARCH XRAY STUDIES AND ARTICLES**

Keyword:  
Cancer Type:  
Choose

https://www.facingourrisk.org/XRAY/night-shift
Summary

Sharon Begley discusses an unconventional new idea about how cancer cells spread (a process known as metastasis) in her recent piece for the website STAT. She states that, "cancer cells spread way earlier than thought, seeding metastases that cause most deaths." (3/28/17)

This article is relevant for:

- Breast cancer survivors
- Her2+ breast cancer
- Men with breast cancer
- Metastatic cancer
- Women under 45
- Women over 45

Contents

- Theory on how cancer spreads
- Questions for your doctor
- What if metastasis can happen earlier
- Studying how metastasis happens
- What does this mean for me
- How scientists believe cancers spread

For years, cancer biology students were taught that tumors initially form in the original organ or tissue (called a primary tumor), and can then spread (metastasize) to a distant organ. Typically, the primary tumor is thought to be
detectable, whether it is found as a lump that can be felt by a person or health care provider or as a mass on a mammogram (https://www.facingourrisk.org/XRAY/early-metastasis) or other imaging technology.

Metastasis is thought to be a very late event in cancer progression. As the primary tumor grows, the cells acquire genetic changes called mutations. Some of these genetic changes are believed to help a few cells break free of the primary tumor and spread to another organ—some ER+ breast cancers, for example, develop the ability to spread to the bone. In this line of thinking, cancer cells that metastasize are thought to be more mutated forms of the cells that make up the primary tumor.

But what if metastatic cancers can form earlier in cancer development than previously thought?

What if some of the cells that can metastasize do not migrate from a primary tumor that is detectable from a lump or imaging such as a mammogram? What if metastatic cancer occurs earlier in cancer development than previously thought, originating from a cell that migrates away from the breast before the primary tumor fully forms.

Today, health care providers use information from a primary tumor’s genetic sequence to help select cancer treatments for patients that hopefully remove all cancer cells so that metastasis does not occur later. This genetic information, however, is acquired later rather than sooner during cancer development. If metastatic cancer can develop early in cancer progression, current prescribed treatments may not be as useful against early cancer cells, which do not have the same genetic information as more mature cancer cells.

Mutations in the cells of both early and late metastatic cancer most likely differ from the primary tumor. But it is important for researchers to learn more about early metastasizing cancer cells, which may not have as many mutations as cells from cancers that have been growing for a longer period of time, and therefore may require different treatment strategies. More research is needed to understand whether these early cells are good targets for therapy and how they can be used if they are.

Understanding how metastasis occurs is critical for developing ways to prevent or treat metastatic cancers

In thisSTAT article, journalist Sharon Begley examines two independent research studies published in the December 2016 issue of Nature by Kathryn Harper (Icahn School of Medicine at Mount Sinai), and Hedayatollah Hosseini (University of Regensburg) and colleagues from various institutions that considered this unconventional theory of metastatic cancer in mice with HER2+ breast cancer, one of the breast cancer subtypes found in humans.

These two studies found that not only can cancer cells spread in mice earlier than previously thought—before the primary tumor is detectable—but these early spreading cells form metastases more efficiently than cancer cells that
spread later in cancer development.

**Research is still in the early stages**

While these findings are interesting and may change how researchers and health care providers think about how cancer spreads, it is important to remember that they are preliminary findings from laboratory studies of mice. **While early studies such as these are crucial for helping to identify disease mechanisms, what happens in mice does not necessarily correlate to what happens in humans.**

In commentary that accompanied the research papers, Dr. Cyrus Chajar of the Fred Hutchinson Cancer Research Center and Dr. Mina Bissell of the Lawrence Berkeley National Laboratory noted that this research was limited to HER2+ breast cancer, and that it is possible that the mechanism of metastasis uncovered by this research may not apply to other cancers or even to other subtypes of breast cancer. Still, Drs. Chajar and Bissell state that these studies have major implications regarding preventative therapies, and that researchers should further understand and "aim to target the characteristic properties" of early metastasis-forming cancer cells.

**What do these results mean for me?**

Clearly, much more work needs to be done in the laboratory to confirm these findings and find ways to apply them to the treatment of human cancers. In the meantime, patients who have had a primary tumor should follow the treatment and screening regimen recommended by their oncologists and be alert to signs of metastasis. And while symptoms of metastatic breast cancer do not always occur, the National Cancer Institute recommends that patients who have had a primary cancer should talk to a health care provider if they experience any of the following:

- Pain and fractures, which may indicate spread to the bone
- Headache, seizures, or dizziness, which may indicate spread to the brain
- Shortness of breath, which may indicate spread to the lung
- Jaundice or swelling in the belly, which may indicate spread to the liver

Posted 3/28/17

Share your thoughts on this XRAY article by taking our brief survey

**References:**

Bergley S. "Cancer cells spread way earlier than thought, seeding metastases that cause most deaths." STAT. Published online on December 14, 2016.


**Disclosure**

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**Questions to Ask Your Doctor**

- What signs and symptoms should I look for if I am concerned that my cancer has spread?
- I have metastatic breast cancer, have both my primary tumor and my metastatic tumor been tumor tested?
- What are the best ways I can be monitored for relapse?
- What are the signs or symptoms of relapse for my breast cancer?

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**SEARCH XRAY STUDIES AND ARTICLES**

**Keyword:**

**Cancer Type:**

Choose

**Relevant for:**

Choose Cancer Type First...

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**Categories:**

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials

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https://www.facingourrisk.org/XRAY/early-metastasis
Article: Parents face challenges when deciding the best time to tell children that they may be at high risk for cancer

SUMMARY

When certain types of cancers run in families, genetic testing can determine whether the cause is hereditary. Genetic testing can help family members understand their cancer risk and make medical decisions to stay healthy. A test result can provide significant insight, but it also creates challenges for parents, because gene mutations that cause hereditary cancers can be passed from mothers and fathers to sons and daughters. People with these mutations must make difficult decisions about when to tell their children that they too may have inherited the mutation. (8/22/2017)

Contents

When should parents share?  Questions for your doctor
Opposing opinions  Guidelines
What do the experts say?  Resources
What does this mean for me?

When should parents tell their children that they (the children) may have inherited a gene mutation that increases their cancer risk?
This question is the basis of Jill Werman Harris’ New York Times article, “When to Tell Daughters About a Genetic Breast Cancer Risk.”

Harris tells the stories of various mothers and daughters, including Angela Durden. When Durden learned that she carried a BRCA() mutation, she decided to tell her 14-year-old daughter Alexis about her own future risk—that she had a 50 percent chance of inheriting Durden’s mutation. Alexis’s first concern was that her mother might get sick or die. However, Durden was unprepared when her daughter said she too wanted to be tested. Durden said, “She said she would get tested as soon as she could and if she was positive, she was going to have a double mastectomy.”

Ann Little, a special-education teacher who is also a BRCA mutation carrier, chose not to tell her youngest daughter, who was 13 at the time, of her mutation status. Little said, “I hated the idea that just as she was starting to develop breasts, she would have to think about losing them.”

Harris also tells the story of Dr. Jill Stoller, a pediatrician with a BRCA mutation. According to Dr. Stoller, her daughter felt that the stress of not knowing was worse than the stress of knowing.

**Opposing opinions**

Should you or shouldn’t you? There are arguments for and against telling young children and adolescents about the possibility of inheriting a gene that increases their cancer risk.

A 2015 study (which Harris cited in her NYT piece, and XRAYs covered in November 2015) by Dr. Angela Bradbury looked at the impact on young girls of knowing that they have increased risk of developing breast cancer. The study, which included 869 mother-daughter pairs (441 pairs were from families with a history of breast cancer, while 428 were not) found that while adolescent girls from high-risk families worried more about the risk of breast cancer, their psychosocial adjustment was similar to their average-risk peers—girls from both groups were generally well-adjusted. This study also found that girls from high-risk families had higher self-esteem compared to their peers. “We aren’t seeing huge red flags about negative outcomes for them,” said Bradbury.

Other experts suggest that teens may benefit from learning that they may inherit a family mutation; because the possibility of developing cancer is distant, adolescents have time to develop coping strategies if they test positive as adults.

However, the study by Bradbury also suggested that girls from high-risk families had more breast cancer-specific distress than girls who were not. Dr. Ruth Oratz, a medical oncology and breast cancer specialist who was not part of Dr. Bradbury’s study, worries that letting children know about a potential genetic risk may “Hamper their teenager’s ability to live freely”
instead of alleviating their anxiety. "Every time someone touches her breast or every time she takes her bra off, you think she's not thinking about it?" she asks.

**What do the experts say?**

Experts do not typically recommend testing minors for BRCA or other mutations related to breast cancer risk, because cancer risk does not increase until adulthood. Experts do recommend that parents discuss the possibility of inheriting a genetic mutation with their daughters by age 25 and with their sons by age 35, as some screening and cancer risk management options would begin at these ages. Discussions of inherited cancer risk should begin at earlier ages in families with individuals who have been diagnosed with breast or ovarian cancer in their mid-twenties.

However, exactly when to tell children about their potential genetic risk falls into a grey area. Because each child is different and each family’s issues and needs are unique, there is no right or wrong age at which to introduce genetic information to your children. "Experts recommend using your child’s age, personality and maturity as a guide," Harris writes. While Dr. Bradbury’s study showed no general difference in psychosocial adjustment between children from high-risk families compared to children from average-risk families, FORCE advisory board members note that, “Although the children in this study did not necessarily feel more distress than their peers, parents should remember that every child and every family is unique.”

**What does this mean for me?**

Dr. Bradbury’s study found that daughters are more likely to be anxious if their mothers are anxious. Therefore, it is important that parents get support for themselves before they talk to their children. For her piece, Harris interviewed Karen Hurley, a clinical psychologist specializing in hereditary cancer and a member of FORCE’s Scientific Advisory Board. Hurley states, “Whether to tell children and when and how to tell them is one of the most common reasons people seek support in the process of genetic testing.”

It is also important for parents to be open with their children when they begin discussing the possibility of inheriting a mutation. “Be straightforward and honest but don’t use confusing euphemisms or dump everything on your child at once,” Harris writes. Finally, after parents share this information with their children, it is important to pay attention to behavioral changes, including how their children are doing in school, whether their social interactions with their peers change, and how they’re sleeping, among other things that may indicate that a child needs more support. If something seems amiss or the child is not coping well, it is important to seek help.

Although Harris interviewed only mothers who had passed a BRCA gene onto their daughters, it is important to note that women and men can carry a BRCA or other high-risk mutation, and that they have a 50% chance of passing it down to any of their sons or daughters. Dr. Stoller said that finding
out her daughter Jenna also carried her same mutation was one of the hardest days of her life. “I understood how my father felt when he found out that he had passed the gene on to me. He said, ‘This is not the legacy I wanted to leave my family.’” However, Hurley reminds parents that they pass many things other than genes onto their children. In discussing a child’s potential to inherit a cancer-predisposing mutation, “You can show them how you cope when life gets hard and what you do in times of uncertainty. You have control about what kind of parent you want to be.”

Posted 08/22/17

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References

New York Times: When to tell daughters about a genetic breast cancer risk


Disclosure

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Study: Pregnancy around the time of a breast cancer diagnosis does not negatively affect survival

**SUMMARY**

The number of women who become pregnant around the time of, or after a breast cancer diagnosis is increasing. However, it is unclear whether pregnancy around the time of a breast cancer diagnosis impacts survival. This recently published study demonstrates that the timing of pregnancy does not negatively affect breast cancer survival rates. (5/24/17)
More women are becoming pregnant before, during, or after they are diagnosed with breast cancer. Although previous studies suggested that pregnancy occurring a year or more after breast cancer treatment did not affect survival, that research did not provide definitive proof.

The researchers classified study participants into 4 groups:

- **No pregnancy:** These women did not conceive from 5 years before to 5 years after their breast cancer diagnosis.
- **Pregnancy before breast cancer:** These women were pregnant from 1 to 5 years before their breast cancer diagnosis.
- **Pregnancy-associated breast cancer:** These women were pregnant from 11 months before to 21 months after a breast cancer diagnosis.
- **Pregnancy following breast cancer:** These women were pregnant from 22 to 60 months after a breast cancer diagnosis.

**Study findings:**

1. The 5-year survival rates for breast cancer patients with no pregnancy right before, during or after breast was 88%.
2. For women who were pregnant before, during, or right after breast cancer they found the following 5 year survival rates:
   - About 85% for women in the pregnancy before breast cancer group
   - About 82% for women in the pregnancy-associated group
   - About 97%, for women in the pregnancy following breast cancer group

**What does this mean for me?**

These findings show that the timing of pregnancy does not negatively affect breast cancer survival. This study also showed that younger pregnant women have a lower rate of survival than older women. However, other studies have shown similar findings in women who are not pregnant. Therefore, it is likely that in this study, the worse outcome of younger pregnant women is related to age at diagnosis rather than to pregnancy.

Posted 5/23/17

**References**


**Disclosure**

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If you are in your reproductive years and have been diagnosed with cancer, or you are considering steps to lower your cancer risk that will interfere with your fertility, you should request referral to a fertility expert.

- The Oncofertility Consortium maintains a national database of healthcare providers with expertise in fertility preservation and treatment of people who are diagnosed with cancer or at high risk for cancer due to an inherited mutation.

Updated: 11/26/2021

The following resources focus on fertility and cancer.

- FORCE fertility resources:
  - Information: Fertility and Cancer Treatment
  - Information: Fertility and family planning
  - Information: Pregnancy after cancer
  - XRAY category: Fertilty
  - Video: Fertility and Parenting Issues for Survivors and Previvors

- Alliance for Fertility Preservation is an organization of healthcare professionals focused on fertility preservation.

- SaveMyFertility.org is a resource for cancer patients who want to learn more about preserving their fertility before and during cancer treatment, and protecting their hormonal health after treatment.

Updated: 11/26/2021

WHO COVERED THIS STUDY?

CTV News
Pregnancy around time of breast cancer diagnosis not risk to survival: study ★★★★★

The Globe and Mail:
Pregnancy around time of breast cancer diagnosis not a risk to mom: study ★★★★★☆

Oncology Nurse Advisor
Does pregnancy increase risk of death in women with breast cancer? ★★★★☆

How we rated the media
IN-DEPTH REVIEW OF RESEARCH

Study background:

The number of women who become pregnant around the time of or after a breast cancer diagnosis is increasing. When treating women with breast cancer, doctors must consider the best approach for treatment as well as the health of both the mother and baby. Pregnant women do not typically receive chemotherapy during the first trimester, and radiotherapy and hormonal therapies are not recommended during pregnancy.

Previous research showed that women who were diagnosed with breast cancer during pregnancy or one year after pregnancy tend to have higher-grade breast cancers, but whether the survival rates of these women are affected is unknown. Additionally, it is not known how long women should wait after breast cancer treatment to try to conceive—some health care providers advise waiting at least 2 years because of a concern that hormones such as estrogen that are released during pregnancy may worsen survival.

Javaid Iqbal and colleagues from the University of Toronto and other institutes published their study results in *JAMA Oncology* in May 2017, comparing overall survival of breast cancer patients who were pregnant before, during, or after diagnosis.

Researchers of this study wanted to know:

Does pregnancy affect survival in women with breast cancer?

Population(s) looked at in the study:

The 7,553 women involved in this study were from Ontario, Canada and had a diagnosis of breast cancer in the Ontario Cancer Registry. Only women with invasive cancer were studied (women who were younger than 20 or older than 45 at the time of diagnosis, women with a personal history of a previous cancer, and women with stage 0 breast cancer (DCIS) were excluded.)

- No pregnancy: These women did not conceive from 5 years before to 5 years after their diagnosis. At the beginning of the study, this group included 5,832 women.
- Pregnancy before breast cancer: Baby was conceived 1 to 5 years before diagnosis. At the beginning of the study, this group included 1,108 women.
- Pregnancy-associated breast cancer: Baby was conceived between the 11 months before a breast cancer diagnosis to 21 months after diagnosis. At the beginning of the study, this group included 501 women.
- Pregnancy following breast cancer: Baby was conceived 22 to 60 months after diagnosis. At the beginning of the study, this group included 112 women.

Study findings:

1. The 5-year survival rates for breast cancer patients were:

   - About 88% for those who did not become pregnant.
   - About 85% for those who were pregnant before diagnosis (baby was conceived 1 to 5 years before diagnosis).
   - About 82% for those who were pregnant at the time of their diagnosis (baby was conceived between the 11 months before diagnosis to 21 months after diagnosis).
About 97%, the lowest risk of death found, for women who were pregnant 6 months or more after their diagnosis.

2. For women with pregnancy-associated breast cancer, younger women (under 35 years old) tended to have poorer overall survival.

3. Women with pregnancy-associated breast cancers were more likely to have ER-negative tumors compared to non-pregnant women (about 37% compared to about 23%).

Limitations:
The Ontario Cancer Registry does not provide some of the data that the researchers collected (tumor size, ER/PR status, etc.) for breast cancer cases that were diagnosed before 2010. Additionally, the researchers had to estimate the time of conception for women who had abortions because their data was unavailable. Finally, the researchers were unable to obtain any information on the use of hormonal treatment.

Conclusions:
This study suggests that pregnancy before, during or after a breast cancer diagnosis does not negatively affect survival, confirming other study results showing that other factors, such as age at diagnosis can impact survival for women who become pregnant around the time of a breast cancer diagnosis. More work should be done to understand the relationship between breast cancer and pregnancy. Meanwhile, this study is hopeful for women who want to have children following a diagnosis of breast cancer as well as women who were pregnant prior to, or at the time of, a breast cancer diagnosis.

Posted 5/23/17

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Cancer Type:

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Categories:

Categories: AND - OR

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk

https://www.facingourrisk.org/XRAY/pregnancy-and-survival
Study: Does scalp cooling help prevent hair loss after chemotherapy?

SUMMARY

Hair loss is one of the most recognized and distressing side effects of some chemotherapies. Two studies looked at the use of scalp cooling therapy to help reduce hair loss after chemotherapy for early-stage breast cancer. (5/15/17)

Update: Based on data from clinical trials, the FDA approved Dignicap scalp cooling device for treatment in patients diagnosed with solid tumors who are receiving chemotherapy.

This article is relevant for:

- Patient undergoing chemotherapy
- Breast cancer survivors
- ER/PR +
- Her2+ breast cancer
- Men with breast cancer
- Ovarian cancer survivors
- Triple negative breast

https://www.facingourrisk.org/XRAY/scalp-cooling-and-hair-loss
Medical Association (JAMA) in February 2017. Both evaluated the use of scalp cooling to prevent hair loss after chemotherapy for early-stage breast cancer.

Why is this study important?
Treatment for breast cancer often includes chemotherapy, which commonly causes hair loss. Although treatment-related hair loss can cause patient distress and anxiety, no options have been available in the United States to help patients avoid this side effect.

Study findings Rugo and colleagues:
Among patients who received scalp cooling therapy (and were followed-up 4 weeks after their last chemotherapy treatment):

1. about 2/3 had lost less than 50% of their hair compared to none of the patients who received the same chemotherapy without scalp cooling therapy.
2. about 27% reported feeling less physically attractive compared to about 56% of patients who did not receive scalp cooling therapy.

Study finding Nangia and colleagues:
Among patients who received scalp cooling therapy (and were followed up after receiving 4 cycles of chemotherapy or at completion of chemotherapy if a patient received more than 4 cycle of chemotherapy)

1. about 1/2 had lost less than 50% of their hair compared to none of the patients who received chemotherapy without scalp cooling therapy.
2. no statistically significant differences in changes in quality of life assessments between baseline and completion of 4 cycles of chemotherapy among the scalp cooling and control groups.

What does this mean for me?
These studies suggest that scalp cooling may be associated with less severe chemotherapy-related hair loss in patients treated for early-stage breast cancer. Although the scalp cooling system used in the Rugo and colleagues study is FDA approved and the scalp cooling system used in the Nangia and colleagues study is awaiting FDA approval, scalp cooling is only available in certain medical centers in the United States. Moreover, more study of the effectiveness and related adverse effects of this new technology is needed. Cost may also be a factor when deciding whether or not to use a scalp cooling device during chemotherapy. Currently, scalp cooling devices in the United States cost about $1500 to $3000 total per patient and are not reimbursed by health insurance. Patients who are interested in scalp cooling should ask their health care providers if it is right for them.

Update: Based on data from clinical trials, the FDA approved Dignicap scalp cooling device for treatment in patients with any type of solid tumors.
Scalp cooling devices prevent hair loss from chemotherapy

Posted 5/15/17

Share your thoughts on this XRAYS article by taking our brief survey

References


Nangia J. “Effect of a Scalp Cooling Device on Alopecia in Women Undergoing Chemotherapy for Breast Cancer The SCALP Randomized Clinical Trial.” JAMA. Published online first on February 14, 2017.

Dignicap commercial website

Hershman DL. “Scalp cooling to prevent chemotherapy-induced alopecia: the time has come.” JAMA. Published online first on February 14, 2017.

Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

Questions to Ask Your Doctor

- Will my treatment result in temporary hair loss?
- Will my hair likely grow back the way it was before?
- What is scalp cooling?
- What side effects can occur after scalp cooling?
- How much does scalp cooling cost? Will it be covered by my health insurance?
- What other therapies are available to help with my hair loss after chemotherapy?
- What other side effects should I expect after chemotherapy?

The following studies are looking at management of treatment side effects:

Multiple cancers

- NCT03581357: Mobile Mindfulness Meditation to Improve Neuropathy in Cancer Survivors. The study examines a mobile app for cancer-related neuropathy in people with breast, colorectal, endometrial, pancreatic, prostate, and other cancers, who have finished treatment and are experiencing neuropathy.

https://www.facingourrisk.org/XRAY/scalp-cooling-and-hair-loss
The following organizations have resources related to treatment side effects:

- FORCE related resources:
  - Information: Chemotherapy side effects
  - Information: Hormone therapy side effects
  - Information: Immunotherapy side effects
  - Information: Radiation side effects
  - Information: Surgery side effects
  - Information: Targeted therapy side effects
  - Information: Wellbeing and survivorship
- XRAY category: Side effects
- FDA MedWatch [online side effect reporting form](#)
- National Cancer Institute [page on cancer treatment side effects](#)
- Centers for Disease Control [page on cancer treatment side effects](#)
- HairToStay helps cancer patients cover the cost of scalp cooling.
- Unite for Her provides financial support for services that help improve quality-of-life in people diagnosed with breast or ovarian cancer.

Updated: 12/03/2021

### WHO COVERED THIS STUDY?

**Chicago Tribune**

Citing: 'Cooling caps' may halt chemo-linked hair loss ★★★★★☆

**New York Times**

Citing: Scalp-cooling caps help prevent hair loss in chemo ★★★★★☆

**NBC News**

Citing: 'Scalp cooling' system helps cancer patients keep hair during treatment ★★★★★☆

How we rated the media

☐ **IN-DEPTH** *(click to expand)*

**IN DEPTH REVIEW OF RESEARCH**

Study background:
Many women who receive chemotherapy experience hair loss, commonly rated by patients with breast cancer as one of the most distressing adverse effects. Though scalp cooling has been available in Europe for a few decades, it has only recently been approved for use in the United States.

Hope Rugo and colleagues from the University of California, San Francisco and Julie Nangia and colleagues published work in the *Journal of the American Medical Association (JAMA)* in February 2017, looking at the use of scalp cooling in patients who received chemotherapy after a diagnosis of early-stage breast cancer.

**Researchers of these studies wanted to know:**

Whether scalp cooling is associated with less hair loss in women who have received chemotherapy for early-stage breast cancer.

**Population(s) looked at in the Rugo and colleagues study:**

The patients involved in this study were women who:

- were at least 18 years old
- were diagnosed with stage I or II breast cancer
- completed a planned chemotherapy regimen in six months (patients who were going to receive sequential or combination anthracycline and taxane therapy were excluded). The chemotherapy regimens included were docetaxel and cyclophosphamide, doxorubicin and cyclophosphamide, docetaxel and carboplatin (with HER2-targeted therapy), weekly paclitaxel, dose-dense paclitaxel, paclitaxel and carboplatin, and docetaxel with HER2-targeted therapy.

The study included 122 women, of whom 77% were white: 106 patients received scalp cooling and 16 patients did not. The researchers used the DigniCap, a silicone cap that was placed on the patients' heads 30 minutes before each chemotherapy cycle. The cap was then cooled to 37 degrees Fahrenheit throughout chemotherapy, and for 90-120 minutes afterward.

The researchers used before-and-after photos to assess hair loss. Patients looked at photographs taken of their hair before the start of each chemotherapy cycle and 3-6 weeks after their last chemotherapy cycle. The patients then estimated the percentage of hair loss using the Dean scale (measurement of 0-4, where 2 represents less than 50% hair loss). An independent panel of people also scored the photos to validate the results.

**Rugo study findings:**

Among patients who received scalp cooling therapy (and were followed up 4 weeks after their last chemotherapy treatment):

1. Approximately 2/3 lost less than 50% of their hair compared to 0 patients who received the same chemotherapy treatment without scalp cooling therapy.
2. About 27% of patients reported feeling less physically attractive compared to about 56% of patients who did not receive scalp cooling therapy.
3. The patients who received scalp cooling therapy reported the following side effects:
   - About 43% reported having headaches that were triggered or made worse by scalp cooling.
   - About 71% of patients reported scalp pain.

**Population(s) looked at in Nangia and colleagues study:**

The patients involved in this study were woman who:
were diagnosed with stage I or II breast cancer

were planning to receive at least 4 cycles of taxane- and/or anthracycline-based chemotherapy. The chemotherapy regimens included were doxorubicin with cyclophosphamide, doxorubicin with fluorouracil and cyclophosphamide, weekly paclitaxel, weekly paclitaxel with carboplatin, docetaxel, docetaxel with pertuzumab and trastuzumab, docetaxel with cyclophosphamide, or docetaxel with carboplatin.

The SCALP randomized clinical trial was conducted at 7 sites in the United States and included 182 women. This study was stopped early due to positive results. At the time the study was stopped, 142 participants were evaluable. The mean age of the patients was 52.6 (10.1) years; 36% (n = 51) received anthracycline-based chemotherapy and 64% (n = 91) received taxane-based chemotherapy.

In this study, scalp cooling was done using the Orbis Paxman Hair Loss Prevention System which was cooled to 37 degrees Fahrenheit and placed on participant’s heads 30 minutes prior to and during and 90 minutes after each chemotherapy treatment.

The researchers assessed hair loss at baseline and after each cycle of chemotherapy using the Common Terminology Criteria for Adverse Events (a scale of 0-2 where 0 represents no hair loss, 1 represents <50% hair loss not requiring a wig or 2 which represents >50% hair loss requiring the use of a wig). Hair loss was assessed by three independent means. Patients did their own self-assessment on their hair loss. They were also assessed by their own doctor and finally by a clinician who was “blinded” (unaware of whether or not each patient received scalp cooling therapy) in order to avoid bias.

Nangia study findings:

Nangia and colleagues reported similar results to the Rugo study.

1. Approximately 1/2 of patients lost less than 50% of their hair compared to 0 patients who received similar chemotherapy treatments without scalp cooling therapy.
   - Estimated hair preservation with anthracycline-based chemotherapy was 16%.
   - Estimated hair preservation with taxanes was 59% and certain taxane-based regimens such as weekly paclitaxel had higher rates of hair preservation versus every-3-week docetaxel.

2. There was variability in the rate of hair preservation between the 7 sites doing the research which is likely due to fitting of the cap, type of chemotherapy, and patient hair characteristics such as hair from people of different ethnicities and hair thickness.

3. Patients who received scalp cooling therapy reported the following side effects: chills, dizziness, headache, nausea, paresthesia (abnormal sensation of tingling, numbness, or burning), pruritus (itching), sinus pain, skin and tissue disorders, skin ulceration, and scalp pain. While no severe adverse effects of scalp cooling were reported in this study, the authors recommend further research to assess longer-term efficacy and adverse effects of scalp cooling during chemotherapy.

Limitations:

Because patients in the Rugo study did not receive anthracycline-based chemotherapy regimens, those results cannot be generalized to all chemotherapy treatments. Additionally, the findings reported in this study were patient-reported results. Unlike trials that include a placebo, these patients knew whether or not they received the treatment, which may have biased the results. Nor was this study was randomized, and the control group (women who did not have scalp cooling treatment) was much smaller than the group that did receive scalp cooling therapy.
The researchers defended their study design by explaining that the chemotherapy regimens used in this study are known to cause hair loss, so they determined that a small study that included a limited number of controls was adequate.

The Nangia study also had some limitations which included variability of results at each site, assessing for successful hair retention after only 4 cycles of chemotherapy when some patients may have received additional cycles. Because this trial was stopped early statistical power was decreased. However, 60 additional patients were enrolled in this trial with the last participant scheduled to complete chemotherapy in early 2017 following which a final analysis will be completed.

There is some concern that scalp cooling may increase the risk of metastasis to the scalp. Because the follow-up in the Rugo (2.5 years) and Nangia (5 years) studies were relatively short a study with a longer follow-up period is needed to rule out this possibility. However, published data demonstrate that the incidence of scalp metastasis following chemotherapy in breast cancer is low, and it is exceedingly rare for the scalp to be the first site of metastasis.

Finally, the UCSF study was partially paid for by the Swedish company Dignitana which manufactures DigniCap while the Baylor study was partially funded by the English company which manufactures the Orbis Paxman Hair Loss Prevention System. Industry-sponsored research is common, and doesn’t necessarily influence results, but it is an important consideration when evaluating potential sources of bias in research studies.

**Conclusions:**

These studies suggest that patients who receive scalp cooling during chemotherapy for early-stage breast cancer have less hair loss than patients who do not receive scalp cooling. The Nangia study suggests that efficacy of scalp cooling may be less at sites where more anthracycline-based chemotherapy is used or where there is less training on proper cap fitting. Thus these substantial differences between sites and technique may impact how effective scalp cooling will be in wider clinical practice.

An accompanying editorial written by Dawn Hershman, MD from Columbia University Medical Center raises questions about the cost of scalp cooling devices and who will pay for them, and notes that more work should be done to study outcomes after scalp cooling treatment. However, she wrote that until targeted therapies are the mainstay and chemotherapy leading to hair loss is no longer needed, “identifying interventions, such as scalp cooling for the prevention of chemotherapy-induced alopecia [hair loss], that reduce or eliminate treatment-associated toxic effects will help ease the distress associated with chemotherapy and may, as a result, improve outcomes for patients with breast cancer.” Interested patients should discuss scalp cooling with their health care providers.

Posted 5/15/17

Share your thoughts on this XRAYs article by taking our brief survey
Study: Common genetic change found in some tumors of patients who relapse after aromatase inhibitor treatment

SUMMARY

About one in five people diagnosed with estrogen receptor-positive (ER+) breast cancer relapse within 10 years after treatment. Researchers and health care providers do not know why this happens. This early research aims to identify a genetic change in the tumor that may cause relapse, but more studies are needed to understand why patients relapse and who is at risk. (5/3/17)

This article is relevant for:
- Patients with ER+ breast cancer
- Breast cancer survivors
- Women under 45
- Women over 45
- ER/PR +

Be part of XRAY:

https://www.facingourrisk.org/XRAY/relapse-after-aromatase-inhibitor
About 20% or more of patients with ER+ breast cancers who have been treated with hormonal therapies such as selective estrogen receptor modulators (SERMs) (e.g. tamoxifen) and/or aromatase inhibitors (AIs) (e.g. letrozole) relapse within 10 years, and some progress to metastatic disease. Researchers and health care providers are unsure why these patients relapse after treatment.

**Study findings:**

1. In about 22% of ER+ breast cancer patients who relapsed after treatment with aromatase inhibitors, a specific genetic change caused much higher-than-normal levels of the CYP19A1 protein, which makes estrogen. This genetic change was:
   - not commonly found in primary breast tumors, and
   - found in very few patients who received selective estrogen receptor modulators, such as tamoxifen.

2. Researchers created cells in the laboratory that made large quantities of CYP19A1. In these cells estrogen was able to bind to estrogen receptors, which decreased response to aromatase inhibitor treatment.

**What does this mean for me?**

This study suggests why some ER+ breast tumors stop responding to treatment. More work is needed to further study aromatase inhibitor resistance. **This research does not change clinical practice.** It is important to note that according to this study, about 20% of patients who receive an aromatase inhibitor develop resistance. Women with ER+ breast cancer should talk with their health care providers to determine which treatment is best for them and how to monitor for signs of relapse after treatment.

Posted 5/3/17

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/relapse-after-aromatase-inhibitor).
WHO COVERED THIS STUDY?

Forbes
Breast cancer may return because cancer cells evolve to create their own food supply

Huffington Post UK
Self-fuelling tumours resist breast cancer drugs, research shows

Daily Mail
Why breast cancer drugs fail for one in four: Scientists discover that tumours can create their own supply of fuel

How we rated the media

IN-DEPTH (click to expand)

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SEARCH XRAY STUDIES AND ARTICLES

Keyword:  

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Categories: □ AND - □ OR

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□ - Basic Science
□ - Cancer Diagnosis
□ - Cancer Risk
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□ - Clinical Trials
□ - Emotional Health
□ - Environmental Exposure
□ - Family & Caregivers
□ - Financial Issues

https://www.facingourrisk.org/XRAY/relapse-after-aromatase-inhibitor
Study: Does eating soy affect the risk of death in breast cancer survivors?

SUMMARY

Is eating soy safe for people who have had breast cancer? This topic has been controversial among health care providers, patients, and survivors for many years because research has yielded mixed results. Some studies suggest people who have been diagnosed with breast cancer should eat more soy products, while other studies recommend they eat less or avoid it altogether. Which should it be? Adding to this research is a new study that asked breast cancer survivors about their soy consumption before and after diagnosis. (4/27/17)
Why is this study important?

Whether women who have had breast cancer should eat foods that contain soy has been debated for many years. Research examining soy’s effect on breast cancers has been mixed; it is still unclear whether women with breast cancer should avoid soy products or eat more soy than they did before their diagnosis.

Study findings:

1. Women diagnosed with breast cancer whose diet contained the highest levels of soy products (more than 1.5 mg daily) before or after diagnosis had a reduced risk of dying from any cause (not just breast cancer) compared to breast cancer survivors who had the lowest level of soy in their diets (less than 0.3 mg daily).

   This association was limited to women who did not previously receive hormone therapy as part of their breast cancer treatment, including those with hormone-receptor-negative (ER/PR-negative) breast cancers.

What does this mean for me?

This study suggests that breast cancer survivors who had a higher dietary intake of soy had less risk of dying from any cause than breast cancer survivors who ate less soy. However, researchers do not completely understand how soy affects breast cancer growth or risk for recurrence. More work needs to be done in this area, especially for women who have ER/PR-positive breast cancer.

It is important to remember that this study adds to what we know about soy consumption and breast cancer but it does not provide definitive conclusions for specific patients. Not all breast cancers are the same, so research that applies to one subtype may not apply to all subtypes. A report by American Cancer Society written by experts in nutrition, physical activity, and cancer survivorship and published in 2012 assessed available research regarding nutritional intake (including soy) for breast cancer survivors; the report stated that, “Current evidence does not suggest that consuming soy foods is likely to have adverse effects on risk of recurrence or survival.”

Ultimately, health care providers know their patients’ cancers and situations best. Women should discuss their concerns with their health care providers, and continue to follow their recommendations regarding soy consumption.

Posted 4/27/17

Share your thoughts on this XRAYS article by taking our brief survey

References

WHO COVERED THIS STUDY?

NPR
For breast cancer survivors, eating soy tied to a longevity boost

Health Day
Also published in:
The same article was also published by the Chicago Tribune

Soy safe, even protective, for breast cancer survivors

NBC News
Soy doesn’t worsen breast cancer and may prevent it, study finds

How we rated the media

IN-DEPTH REVIEW OF RESEARCH

Study background:
Soy consumption by people with breast cancer is controversial among researchers and health care providers, and that controversy often confuses patients and survivors. Some research shows that dietary soy acts against breast cancer development by decreasing the amount of estrogen made by the body. On the other hand, other research shows that dietary soy can act like estrogen, activating the signaling pathways that encourage breast cancer growth.

While studies from China have consistently found a lower risk of breast cancer recurrence and/or risk of death associated with higher soy consumption in women, studies conducted in the United States have yielded mixed results.

Fang Fang Zhang and colleagues from Tufts University and other institutions published work in the journal Cancer in March 2017 looking at soy consumption and risk of death from any cause (not just breast cancer) in women who have been diagnosed with breast cancer.

Researchers of this study wanted to know:
How does eating soy products affect the risk of death in women who have had breast cancer?

Population(s) looked at in the study:
The researchers used the Breast Cancer Family Registry to survey women from San Francisco, New York City, Philadelphia, Utah, and Ontario (Canada) who had invasive breast cancer. Information on the women’s tumor hormone status (estrogen and progesterone receptors) was taken from pathology reports or from cancer registry records. Researchers obtained mortality data in various ways, including annual telephone contacts and questionnaires.
These women completed questionnaires that included information on their diets. Of the 6,235 women who participated, 4,769 returned the questionnaire within 5 years before they were diagnosed (pre-diagnosis), while 1,466 returned the questionnaire within 5 years after they were diagnosed (post-diagnosis). The women were asked how frequently they consumed certain foods (including soy) and the portion size. Average follow-up was 113 months (9.4 years), during which 1,224 deaths occurred.

**Study findings:**

1. Women with breast cancer whose diets contained the highest levels of soy products (more than 1.5 mg daily), whether pre- or post-diagnosis, had a reduced risk of dying from any cause (not just breast cancer), compared to breast cancer patients who had the lowest levels of soy in their diets (less than 0.3 mg daily).

   - This association was limited to women who had hormone-receptor-negative (ER-/PR-) breast cancers and women who did not previously receive hormone therapy as part of their breast cancer treatment.

**Limitations:**

Because the researchers used a self-reporting survey to measure soy intake, the results are subject to certain data collection errors, including the possibility that participants incorrectly remembered how often they ate a particular food or how much of it they ate. (Data from women whose reported total calorie intake was much higher or much lower than the average caloric intake of other participants were considered to be unreliably reported and were excluded from the results.) Women who had higher soy intake were more likely to be Asian American, young, premenopausal, physically active, more educated, not overweight or obese, nonsmokers, and either did not drink alcohol at all or drank less than 7 alcoholic drinks per week. To ensure that the effect on risk was due to soy consumption and not any of these other factors, the researchers adjusted for this information in their mathematical models. Finally, the researchers looked only at all-cause mortality, meaning deaths that were not breast cancer specific; they were unable to look at breast cancer recurrence. The researchers did not have additional information on any other diseases that the women may have had, which may have also increased the risk of death.

**Conclusions:**

This study suggests that women who have breast cancer and regularly consume soy products have a lower risk of dying from any cause. However, more work needs to be done to understand and confirm these findings. **Breast cancer patients should continue to follow their doctor’s recommendations regarding soy consumption during and after treatment.** Women who are worried about their dietary intake of soy or any other nutrients should discuss their concerns with their health care providers.

Posted 4/27/17

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/soy-and-survival).

**References**


Study: FDA report claims women with breast implants may be at risk for rare cancer

SUMMARY

THIS INFORMATION HAS BEEN UPDATED. The FDA issued an update in March, 2018 about Breast Implant Associated Anaplastic Large Cell Lymphoma (BIA-ALCL). This was covered in a more recent XRAY review. On 07/25/19, the FDA announced a recall of Allergan BIOCELL textured implants and expanders, due to their association with BIA-ALCL. This was also covered in a more recent XRAY review.

Recent headlines highlighted an FDA report stating that patients with breast implants may be at increased risk for a rare type of non-Hodgkin lymphoma. What is the scientific evidence behind this claim? (4/21/17)

This article is relevant for:
- Women who had or are consideration breast reconstruction with implants
- Breast cancer survivors
- Women under 45
- Women over 45

https://www.facingourrisk.org/XRAY/implant-lymphoma-risk
A possible increased risk of anaplastic large cell lymphoma (ALCL), a rare type of non-Hodgkin lymphoma, in women who have breast implants.

**Why is this FDA report important?**

Patients who are making decisions about breast reconstruction or breast augmentation with implants should be informed of any possible link between anaplastic large cell lymphoma and breast implants. Their health care providers should also be aware of this link so that they can properly monitor women who have breast implants.

**Study findings:**

1. As of February 1, 2017, the FDA has received 359 medical device reports, including 9 deaths, of breast implant-associated anaplastic large cell lymphoma (ALCL):
   - 203 cases involved textured implants; 28 involved smooth implants.
   - 186 cases involved silicone implants; 126 involved saline implants.

2. As this data was derived from a compilation of reports rather than a formal research study, the percentage of women with implants who develop this rare lymphoma cannot be calculated.

**What does this mean for me?**

Please read our [more recent XRAY reviews](https://www.facingourrisk.org/XRAY) to learn more about what is currently known about BIA-ALCL and FDA recommendations.

Based on the current literature and medical device reports, the FDA reported a link between breast implants and anaplastic large cell lymphoma (ALCL). However, the FDA report states, “If you have breast implants, there is no need to change your routine medical care and follow-up.” Women with implants should follow standard medical recommendations, which include:

- Knowing the look and feel of your natural or reconstructed breasts, and notifying health care providers immediately you notice any change.
- Discussing the possibility of having breast MRI (magnetic resonance imaging) to check for implant ruptures, particularly if you have silicone implants.

Importantly, the FDA also advises that, “Breast implant-associated anaplastic large cell lymphoma is a very rare condition.” Patients should weigh the risks and benefits of getting breast implants with their health care providers. While women with breast implants may have increased risk of developing anaplastic large cell lymphoma compared to women who do not have implants, the research literature referenced in this FDA report suggests that the risk is “very low.” During 2017, the American Cancer Society predicts diagnosis of 255,180 breast cancer cases compared to 72,240 non-Hodgkin

lymphoma cases, of which only 1,500 to 2,100 will be ALCL. Using these figures, the occurrence of ALCL in the United States is about 5 cases per million people.

Common symptoms of Non-Hodgkin lymphoma are:

- Enlarged lymph nodes
- Fever
- Sweating and chills
- Weight loss
- Fatigue
- Swollen abdomen
- Feeling of fullness
- Chest pain/pressure
- Shortness of breath/cough

Breast cancer survivors or people at high risk for breast cancer who experience these symptoms should discuss them with their health care providers.

Posted 4/21/17

Share your thoughts on this XRAYS article by taking our brief survey
WHO COVERED THIS STUDY?

CNN
9 deaths and rare cancer linked to breast implants, FDA says ★★★★★☆☆

Forbes
FDA links breast implants to cases of rare blood cancer ★★★★★☆☆

New York Times
9 deaths are linked to rare cancer from breast implants ★★★★★☆☆

CBS News
9 deaths linked to rare cancer from breast implants ★★★★★☆☆

How we rated the media

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Keyword: 
Cancer Type: 
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- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health

https://www.facingourrisk.org/XRAY/implant-lymphoma-risk
Nearly half of breast cancer patients experience a severe side effect after treatment

**SUMMARY**

While clinical trials track treatment side effects, fewer studies look at the burden of side effects on women undergoing breast cancer treatment or compare the side effects of different treatments. This study looks at the severity of side effects experienced by women treated for early-stage breast cancer. (4/11/17)

**STUDY AT A GLANCE**

This study is about:

Documenting the frequency, severity, and burden of side effects (including nausea/vomiting, diarrhea, constipation, pain, arm swelling, difficulty breathing, and breast skin irritation) that women experience after treatment for early-stage (I or II) invasive breast cancer.
Nearly half of breast cancer patients experience a severe side effect after treatment.

**Why is this study important?**

Few studies have looked at the full spectrum of side effects that women experience after treatment for early-stage breast cancer. It is important that health care providers are aware of the side effects that breast cancer patients can experience after treatment so they can incorporate this information into their treatment and survivorship plans with patients and provide early intervention when necessary.

**Study findings:**

1. 45% of breast cancer patients reported at least one “severe” or “very severe” side effect after treatment.
2. Factors associated with a more severe side effect after treatment were:
   - Receiving chemotherapy alone or in combination with radiation
   - Latina ethnicity

**What does this mean for me?**

This study showed that a substantial number of women experience side effects after breast cancer treatment. More work needs to be done to better understand and characterize the side effects associated with treatment. In the meantime, patients who experience side effects or who are about to start treatment should discuss their symptoms and/or concerns with their health care providers.

Posted 4/11/17

Share your thoughts on this review by taking our brief [our brief survey](https://www.facingourrisk.org/XRAY/treatment-side-effects).

**References**


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**Questions to Ask Your Doctor**

- Who should I call if I experience a side effect?
- Do all women experience side effects after breast cancer treatment?
- What are potential side effects I may have after breast cancer treatment?
- What are ways to alleviate the side effects that I may experience after breast cancer treatment?

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**Open Clinical Trials**

The following studies are looking at management of treatment side effects:

**Multiple cancers**

- NCT03581357: [Mobile Mindfulness Meditation to Improve Neuropathy in](https://www.facingourrisk.org/XRAY/treatment-side-effects)
Nearly half of breast cancer patients experience a severe side effect after treatment

The following organizations have resources related to treatment side effects.

- FORCE related resources:
  - Information: Chemotherapy side effects
  - Information: Hormone therapy side effects
  - Information: Immunotherapy side effects
  - Information: Radiation side effects
  - Information: Surgery side effects
  - Information: Targeted therapy side effects
  - Information: Wellbeing and survivorship

- XRAY category: Side effects

- FDA MedWatch online side effect reporting form
- National Cancer Institute page on cancer treatment side effects
- Centers for Disease Control page on cancer treatment side effects
- HairToStay helps cancer patients cover the cost of scalp cooling.
- Unite for Her provides financial support for services that help improve quality-of-life in people diagnosed with breast or ovarian cancer.

Updated: 12/03/2021

WHO COVERED THIS STUDY?

Medical Daily

Breast cancer treatment side effects: half of early-stage patients report severe symptoms ★★★★☆

TIME

Half of women have serious side effects from breast-cancer treatment ★★★★★☆☆

iTechPost

Breast cancer treatment: half of women experience stern side effects ★★★★★☆

How we rated the media

[IN-DEPTH (click to expand) ]

IN DEPTH REVIEW OF RESEARCH

https://www.facingourrisk.org/XRAY/treatment-side-effects
Nearly half of breast cancer patients experience a severe side effect after treatment

Study background:
Health care providers always take care to ensure that a treatment is greater than its potential risks, but treatment can be more difficult with drugs such as cancer treatments where the dose needed often causes side effects.

While information is available regarding treatment side effects from clinical trial studies and health care claims, few studies have thoroughly examined the side effects that breast cancer patients experience after treatment outside of those settings. Additionally, participants of these studies are typically patients with late-stage breast cancer. Christopher Friese and colleagues from the University of Michigan School of Nursing and other institutions published research in 2017 in the journal Cancer that studied the side effects of women who were treated for their early-stage breast cancer.

Researchers of this study wanted to know:
What are the side effects, severity of those side effects, and patient burden associated with treatment for early-stage (I or II) invasive breast cancer?

Population(s) looked at in the study:
This study used data from 1,884 women, ages 20-79, with early-stage (I or II) invasive breast cancer of any type. Women who had stage III or IV cancer or tumors bigger than 5 cm were excluded. The data was taken from the Los Angeles County and Georgia Surveillance, Epidemiology, and End Results (SEER) programs. Among the participants, 1,057 women were white, 321 were black, 315 were Latina, 141 were Asian and 50 were of unknown race or ethnicity. The patients received primary breast surgery (lumpectomy, unilateral or bilateral mastectomy) and may or may not have had radiation, chemotherapy, or both radiation and chemotherapy.

The researchers mailed surveys about two months after each woman’s surgery, asking patients to rank the severity of their side effects, including nausea/vomiting, diarrhea, constipation, pain, arm swelling, difficulty breathing, and breast skin irritation. Patients were also asked to fill out a survey about their physical health (the PROMIS measure) and health care services they used because of side effects. This allowed the researchers to measure the patient burden of side effects after treatment.

Study findings:
1. 45% of breast cancer patients reported that they experienced at least one “severe” or “very severe” side effect after treatment.
2. Factors associated with a more severe side effect were:
   - Receiving chemotherapy alone or in combination with radiation
   - Latina ethnicity
3. An association was observed between patients’ PROMIS score (measure of physical health) and side effects experienced. Patients who did not experience side effects had higher PROMIS scores, indicating better physical health, while patients who did experience side effects had lower PROMIS scores, indicating worse physical health.
4. 9% of women reported unscheduled visits to their health care providers to manage their side effects; 5% of women visited an emergency department or hospital for their side effects.

Limitations:
Nearly half of breast cancer patients experience a severe side effect after treatment.

This study was conducted through patient surveys; researchers did not have access to patients’ health records. Studies such as these that rely solely on patients’ memories can include errors due to patients’ recall (for example, not remembering a side effect experienced or remembering it as more or less severe than it would be classified by a health care provider). Additionally, while the researchers recruited a fairly diverse group of women, because the study was limited to two geographic regions (Los Angeles and Georgia), the study conclusions may not be applicable to other areas. Finally, this study only included women with early-stage breast cancer; most had ER+/HER2- tumors. Additional work is needed to examine the effect in more advanced breast cancers. The researchers’ analysis did not separate early-stage breast cancers into different subtypes—depending on a patient’s subtype, individuals may have received different treatments compared to other patients, so the results may not be widely applicable to all patients.

Conclusions:

This study suggests that almost half of women with early-stage invasive breast cancer experience at least one severe or very severe side effect after treatment. The study authors identified many clinical implications from this study, writing: “The toxicity burden faced by patients may be greater than acknowledged by clinicians, and warrants routine assessment during and between clinical visits. Differential toxicity patterns identified in this diverse, population-based sample of women may help clinicians when they review the risks and benefits of breast cancer treatment options.”

Posted 4/11/17

Share your thoughts on this review by taking our brief our brief survey.

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https://www.facingourrisk.org/XRAY/treatment-side-effects
Study: Routine breast cancer screening leads to overdiagnosis

SUMMARY

Routine breast cancer screening for women of average risk has been controversial for many years because some believe that the benefits do not outweigh the risks. Recent headlines covering a study in Denmark suggests that routine breast cancer screening leads to “overdiagnosis” of breast cancer. (4/4/17)
A goal of breast cancer screening programs is to reduce the number of advanced cancers, hopefully providing less invasive treatment for patients, decreasing disease burden (including financial cost and general quality of life), and resulting in fewer deaths from the disease. However, screening programs may be leading to “overdiagnosis,” defined as identifying tumors that would not have caused symptoms or spread had they not been detected. The risk associated with overdiagnosis is that women may undergo treatment that they may not need and would not have if the screening program had not uncovered the tumor. As there are physical, emotional, and financial effects of treatment, the risk of overdiagnosis and overtreatment is considered when weighing the risks and benefits of breast screening programs.

**Study findings:**

1. More nonadvanced tumors were identified when routine screening programs were introduced in Denmark.

2. The number of “overdiagnosed” tumors (including both invasive tumors and DCIS) were calculated as the difference between the number of tumors before and after screening programs were implemented. The rate of overdiagnosis ranged from about 16% to about 48%, depending on the specifics of women included in the estimate (age range, where they lived, etc.) and the type of tumor (invasive cancer or DCIS).

**What does this mean for me?**

This study suggests that more breast cancer patients were overdiagnosed after routine screening was implemented in Denmark. However, the results from this study are not conclusive and more work needs to be done. The study authors considered a tumor to be overdiagnosed if it was a nonadvanced cancer (a tumor of 20 mm or smaller), with the assumption that it would not progress further. Although they associated advanced tumors with mortality, they did not have data to back up this assumption.

It is important to remember that this study looked at routine screening, and did not include screening that was triggered by a lump or other breast cancer symptom. Also critical to remember is that this study included women with varying risk for breast cancer; it did not focus only on screening of women at increased risk of breast cancer due to family history and/or mutations in **BRCA** (or other genes associated with increased cancer risk). **Patients and their health care providers should work together to determine a patient’s optimal breast cancer screening interval based on her personal breast cancer risk factors, including family and personal history of cancer and/or genetic mutation associated with increased cancer risk.**

Posted 4/4/17

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/screening-and-overdiagnosis).
References:


American Cancer Society. American Cancer Society recommendations for early breast cancer detection in women without breast symptoms. 2015.


The following organizations have breast cancer screening resources.

- **FORCE resources:**
  - Information: [Breast Cancer Screening](#)
  - XRAY category: Breast Cancer Screening
  - Video: [Screening and Nonsurgical Methods of Prevention for Women at High Risk for Breast Cancer](#)

- **National Breast and Cervical Cancer Early Detection Program (NBCCEDP)** provides low-income, uninsured and underinsured women with access to breast screenings (including MRIs for high-risk women in some states) and diagnostic services.

- **American Breast Cancer Foundation’s Breast Cancer Assistance Program** provides aid for breast cancer screenings and diagnostic tests for uninsured and underserved individuals, regardless of age or gender.

Updated: 01/02/2022

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**WHO COVERED THIS STUDY?**

**CNN**

*Third of breast cancer patients treated unnecessarily, study says* ★★★★☆

**NBC News**

*Mammograms aren’t perfect, American Cancer Society top doc says* ★★★★☆

**Forbes**

*Do screening mammograms cut breast cancer deaths or lead to overtreatment? Probably both* ★★★★☆

**The New York Times**

*The downside of breast cancer screening* ★★★★☆

How we rated the media

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**IN-DEPTH (click to expand)**

**IN DEPTH REVIEW OF RESEARCH**

*Study background:*
Breast cancer screening is a controversial topic—health care providers and researchers are not sure when women at average risk should start screening or how often they should be screened. One reason for the controversy is that health care providers and researchers are still trying to determine the benefit of screening: does it prevent more advanced-stage breast tumors, and will doing that lead to fewer deaths due to breast cancer? Or does screening catch smaller, nonadvanced tumors that may never lead to advanced disease or death?

Karsten Jørgensen and colleagues from The Nordic Cochrane Centre and other institutions published work in the *Annals of Internal Medicine* in March 2017, using data collected through two Danish cancer registries to determine whether overdiagnosis of breast tumors was occurring.

**Researchers of this study wanted to know:**

What types of breast tumors are found through routine breast cancer screening and what rate of overdiagnosed breast cancer occurred after screening was implemented in Denmark?

**Population(s) looked at in the study:**

The researchers collected data from women in two registries: the Danish Breast Cancer Group (DBCG) and the Danish Cancer Registry (DCR). These women were between the ages of 35 and 84 and had tumors that were either nonadvanced (20 mm or smaller) or advanced (greater than 20 mm). Diagnoses of both invasive cancer and ductal carcinoma in situ (DCIS) were considered in this study. Women in the study received screening every other year.

**Study findings:**

1. When routine screening programs were introduced in Denmark, more nonadvanced tumors were identified.

2. The number of overdiagnosed tumors (including both invasive tumors and DCIS) were calculated as the difference between the number of tumors before and after screening programs were implemented in Denmark. The rate of overdiagnosis ranged from about 16% to about 48%, depending on the specifics of the women included in the estimate (age range, where they lived, etc.) and the type of tumor (invasive cancer or DCIS).

**Limitations:**

This research study looked at the number of nonadvanced and advanced breast tumors, but it did not include data on breast cancer mortality. This means that the study authors can claim incidence of either type of tumors increasing or decreasing, but it cannot connect that data to mortality, because they do not know how many of the nonadvanced tumors would have advanced and caused death. Additionally, this study was done in Denmark, and may not directly translate to the United States. Also, this was a retrospective study; because the authors did not collect their own data, some of it may have been incomplete, possibly excluding or including factors that may have affected the findings and control for them. Finally, this study included women with or without a family/personal history of breast cancer, and women with or without genetic mutations that put them at higher risk for developing breast cancer. Because of this, it is not known whether the study findings would have been different if the study included only women at higher risk of breast cancer.

**Also of importance is the fact that the published study results rely on the authors’ definition of “overdiagnosis” and does not consider the benefits to women whose cancers were caught by routine screening before they had symptoms. This study also excluded women whose tumors were tested with prognostic tests that are now widely used to help guide treatment decisions.**

**Conclusions:**

https://www.facingourrisk.org/XRAY/screening-and-overdiagnosis
This study suggests that overdiagnosis occurs after breast cancer screening. However, more work needs to be done to determine which women benefit or don’t benefit from screening, and when and how often to screen. In an accompanying editorial, Dr. Otis Brawley of the American Cancer Society reviewed other data showing overdiagnosis of breast cancer, and argues that “a significant minority” of breast cancers detected through routine screening do not threaten the health or life of the women. Identifying which of these tumors do not require aggressive treatment is an area of active research, and as Dr. Brawley writes, “...we must carefully examine screening, realize its limitations, maximize its effectiveness, and try to improve it.”

Not all women have the same risk for breast cancer, and a “one-size-fits-all” screening guideline for women does not exist. Current guidelines already call for distinct screening for women who are known to be at high risk for breast cancer due to mutations in BRCA or other genes associated with increased cancer risk, a strong family history of breast cancer, and/or history of radiation treatment to the chest. In some cases, guidelines recommend combining magnetic resonance imaging (MRI) with mammography.

Current breast cancer screening guidelines for women at average risk of breast cancer are controversial and differ among reputable organizations. The United States Preventative Services Task Force (USPSTF) recommends a screening mammogram every other year for women ages 50-74. Guidelines of numerous other organizations, including the American Cancer Society (ACS), the National Comprehensive Cancer Network (NCCN), the American Medical Association (AMA), the American College of Radiology (ACR), and the American Congress of Obstetricians and Gynecologists (ACOG) recommend annual screening mammograms beginning at younger ages—the ACS recommends age 45, while the other organizations recommend age 40. Recently, the NCCN added that women and their doctors consider using 3D mammography (mammography), which is not addressed in this study. Patients should work with their health care providers to determine when and how often they are screened, and to be sure to discuss all of their concerns.

Posted 4/4/17

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Relevant for:

Choose Cancer Type First...

Categories:

Categories: □ AND - □ OR

- Alternative Treatments
- Basic Science
- ...
Study: Angelina Jolie spoke out on BRCA testing: Did genetic testing increase?

**SUMMARY**

Angelina Jolie published an editorial in the New York Times in 2013 about her choice to have a double mastectomy after finding out she was positive for a BRCA1 mutation. Researchers from a recent study claim that her celebrity endorsement of BRCA testing may have missed its target audience (previvors), due to the increase in BRCA testing following publication of the editorial but a decrease in the number of mastectomies performed. However, the study failed to take into account that many women without breast cancer do not pursue mastectomy in the months following genetic testing. (1/4/17)

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**STUDY AT A GLANCE**

**This study is about:**

Whether rates of genetic testing and mastectomy were affected by Angelina Jolie’s 2013 *New York Times* editorial on her decision to have a preventative mastectomy because she carried a BRCA1 mutation.

**Why is this study important?**

This article is relevant for:

- People interested in genetic testing for an inherited mutation
- Breast cancer survivors
- Women under 45
- Women over 45
- Previvors

Read the article that we reviewed

https://www.facingourrisk.org/XRAY/angelina-brca-testing
Celebrity endorsements commonly appear on television, in magazines and on the Internet, ranging from skin care products to fad diets. But do these endorsements affect consumer behavior? Not much research is available on this topic. This study compares the time period immediately following Angelina Jolie’s editorial to the period before to see if her editorial resulted in any major changes.

**Study findings:**

1. In the 15 days before Ms. Jolie’s 2013 editorial was published, 0.71 BRCA tests were performed per 100,000 women, compared to 1.13 BRCA tests per 100,000 women in the 15 days after the editorial was published.
   - This increase represents about 4,500 additional BRCA tests at an estimated cost of $13.5 million dollars, assuming the average cost per test was just over $3,000.

2. About 10% of women who had BRCA testing in the months before the editorial had mastectomies. In the 60 days after the editorial was published, about 7% of women who had BRCA testing also had mastectomies.

3. Overall mastectomy rates did not change in the months following Ms. Jolie’s editorial.

**What does this mean for me?**

The authors of this study wrote in their conclusion, “Celebrity announcements in the social media age can raise awareness and use of preventive care by a large and broad audience, although their ability to target subpopulations of interest may be limited.”

The authors concluded that increased BRCA testing and decreased overall mastectomy rates during this time meant that the additional women who were tested did not carry as many BRCA mutations because they did not get mastectomies. The researchers believe that instead of targeting people who were positive for a BRCA mutation, the editorial in fact targeted those who were not as likely to carry a BRCA mutation.

*While the authors’ conclusions were based on one interpretation the data, it is not necessarily accurate.* This study was flawed (details are discussed in the Limitations section (below). Most notably, the authors’ conclusion that Jolie’s editorial did not reach the target population (women with a family history of breast, ovarian, *fallopian tube* (I), or peritoneal cancer) was based on insurance data. However, to have BRCA testing ordered and covered through insurance in 2013, patients most likely had to have a family history of breast/ovarian cancer, *Ashkenazi Jewish* (I) ancestry, and/or a personal history of these cancers at a young age.

https://www.facingourrisk.org/XRAY/angelina-brca-testing
Patients who are concerned about a genetic cause of breast cancer should talk to a genetics professional, such as a genetic counselor or medical geneticist. These health care providers will assess the patient’s personal and family history of cancer and determine if genetic testing is right for them.

Posted 1/4/17

Share your thoughts on this XRAYS article by taking our brief survey

References


NCCN guidelines recommend genetic counseling and testing for people without cancer who have the following family history:

- A relative who has tested positive for an inherited mutation in a gene that increases cancer risk.
- One or more first- or second-degree relatives with breast cancer and any of the following:
  - diagnosed at age 45 or younger
  - triple-negative breast cancer
  - two separate breast cancers, with the first diagnosis at age 50 or younger
  - male breast cancer
- One or more first- or second-degree relatives with:
  - colorectal cancer before age 50
  - endometrial cancer before age 50
  - ovarian, fallopian tube, primary peritoneal cancer
  - rare or childhood cancers
- One or more first-degree relatives with:
  - metastatic or high-grade prostate cancer
  - pancreatic cancer
- Two or more relatives on the same side of the family diagnosed with any combination of the following at any age:
  - breast cancer
  - pancreatic cancer
WHO COVERED THIS STUDY?

STAT
Were women foolish to follow Angelina Jolie into BRCA cancer gene testing?

WBUR
Angelina Jolie drives up BRCA test rates but health benefit questionable

The unintended consequence of Angelina Jolie’s viral breast cancer essay
The unintended consequence of Angelina Jolie’s viral breast cancer essay

VOX
Angelina Jolie’s breast cancer op-ed may have cost the health system $14 million in unnecessary tests

CNBC
Angelina Jolie’s breast cancer op-ed cost the health system $14 million in unnecessary tests

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Angeline Jolie wrote an editorial in the New York Times in 2013 to increase awareness of BRCA testing and explain her life choices following her positive BRCA test result. Drs. Sunita Desai and Anupam Jena from Harvard Medical School’s Department of Health Care Policy published research in the British Medical Journal examining changes in BRCA testing and mastectomy rates that may have resulted from the publication of Ms. Jolie’s editorial.

Researchers of this study wanted to know:
Do celebrity endorsements result in population level change in health-related behavior?

Population(s) looked at in the study:
This study looked at information from 9,532,836 women who had claims in the Truven MarketScan commercial claims database, which includes health insurance claims for over 50 million patients.

Study findings:
1. In the 15 days before Ms. Jolie’s 2013 editorial was published, .71 BRCA tests were performed per 100,000 women, compared to 1.13 BRCA tests per 100,000 women in the 15 days after the editorial was published.
This increase represents about 4,500 additional BRCA tests costing $13.5 million dollars, assuming the average cost per test was just over $3,000.

This increase did not occur during the same time period in 2012.

2. About 10% of women who had BRCA testing in the months before the editorial had mastectomies. In the 60 days after the editorial was published, about 7% of women who had BRCA testing got mastectomies. A "similar pattern" was found 90 and 180 days after testing.

3. Overall mastectomy rates for all women (tested or not tested) did not change in the months following Ms. Jolie's editorial.

Limitations:
The authors acknowledge in their limitations section that they “did not measure benefits associated with knowing one’s BRCA status such as peace of mind or increased vigilance after learning one’s risk factors.” Additionally, they were unable to identify from their data which mastectomies were preventative. Their study population also excluded some people, such as Medicare enrollees.

The authors used the post-testing mastectomy rate as an indirect way to measure the number of women who tested positive for BRCA mutations. They claim that the increased number of women who were tested after the editorial was published had a lower probability of having a BRCA mutation than women who tested before the editorial. Using mastectomy as a measure of positive BRCA mutation test results presents several problems. It assumes that mastectomy follows a positive test result, but we know that not all women who test positive for a mutation choose risk-reducing mastectomy.

First, although national guidelines state women with BRCA mutations may “consider” mastectomy, it is not a hard and fast recommendation. Many women instead choose to undergo increased screening or take risk-reducing medication to manage their increased risk of breast cancer. Many women with breast cancer who meet guidelines for genetic testing may use BRCA testing to help them decide between treating their cancer with lumpectomy or mastectomy. In these cases, mastectomy would occur within a few months of testing. But the study authors argue that women went to their doctors to request testing as result of reading the editorial; these women were presumably previvors (without cancer), who had more time to consider whether or not they wanted to pursue risk-reducing mastectomies. Even those who decide to manage breast cancer risk by having a risk-reducing mastectomy will not necessarily have the surgery within the timeframes used in this study. Recovery from mastectomy, particularly when paired with reconstruction, requires several weeks of rest. Women without cancer are not pressed to schedule mastectomy for treatment; they can delay scheduling their surgery until it syncs with their work and/or family schedule.

Second, national guidelines recommend that women who test positive for a BRCA mutation have their ovaries and fallopian tubes removed. In many cases, women with BRCA mutation choose to have their ovaries and fallopian tubes removed before having mastectomy. In 2013, the recommendation was to have this risk-reducing surgery around ages 35-40 and after the completion of childbearing. Women who tested after age 40 might have felt more compelled to have their ovaries removed first. Indeed, over half of the women who underwent BRCA testing in this time period were over age 45. Even those under age 40 may have chosen to have their ovaries and fallopian tubes removed before pursuing mastectomy, because the surgery has a shorter recovery time and requires less time off work. Removal of the ovaries also decreases breast cancer risk, and can be used in conjunction with increased screening to manage breast cancer risk.
The study authors also wrote that mastectomy rates may have increased after the time captured by their study period. This is something that should not be overlooked and should be studied if researchers want to make the claim that mastectomy rates decreased in a specific time period—mastectomy is a big decision and major surgery, and not all women can immediately make the decision and drop everything in a month after finding a positive BRCA mutation to get a mastectomy done. This is particularly true for women who do not have breast cancer and elect to have a mastectomy for prevention, and not as part of cancer treatment, which is precisely the group “targeted” by the Jolie editorial.

Ultimately, the researchers in this study did not have direct data to back their claim that the women who had genetic testing after Jolie’s editorial were not those at risk of having a mutation, because the researchers do not know the exact number of people who tested positive for BRCA, their personal or family histories of cancer, or if there was an increase in other medical services such as breast MRI (), surgical removal of ovaries and fallopian tubes, or prescriptions for risk-reducing medications that would follow a positive BRCA test result.

Finally, the authors did not put their research in the context of the current (2016) genetic testing landscape. Testing is offered by more labs and becomes increasingly cheaper as time goes on. Genetics professionals no longer only test for BRCA mutations, as research has identified many new breast/ovarian cancer risk-increasing genes such as PALB2 (), ATM (), CDH1 (), PTEN () and more, which are easily tested for on gene panels.

Conclusions:
The authors in this study found that BRCA testing increased in the 15 days following Angelina Jolie’s New York Times article, but this increase was not correlated with an increase in mastectomy rates in the 60 days following the publication. Based on this premise, the authors concluded that celebrity endorsements reach a broad audience that may not be the targeted population. More definitive data is needed to prove this claim. Regardless of the results of this study, patients with a personal or family history of ovarian cancer or breast cancer before age 50 should not hesitate to see a genetics professional to determine if they should consider genetic testing.

Assessing media coverage of this study is difficult because while many media articles accurately reported on the researchers claims, few dug into the paper or talked to outside experts who could have commented on the many limitations of the methodology. In the end, this study shows that the number of BRCA tests in the United States increased in the 15 days following Ms. Jolie’s editorial. However, the conclusions about whether or not these women had a mutation based on whether or not they had a mastectomy are but one interpretation of the data and should have been called out by the media.

Posted 1/4/17

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https://www.facingourrisk.org/XRAY/angelina-brca-testing
Study: High vitamin D levels at breast cancer diagnosis may be associated with a better prognosis

Summary

Vitamin D is most known for its role in maintaining bone health but vitamin D has additional roles in keeping us healthy. In this study, researchers found that breast cancer patients who had the highest amounts of vitamin D in their blood (slightly over the recommended levels) had better health outcomes, including overall survival, than women with lower amounts of vitamin D. This finding adds to the growing evidence for the role of vitamin D in cancer, but it does not change how breast cancer is prevented or treated. (1/10/17)
Why is this study important?

Vitamin D is important for bone health and is also implicated in other bodily processes. Some research suggests that vitamin D is involved in breast cancer, but its role is not well understood. Researchers in this study wanted to know if there is a link between the level of vitamin D in a woman’s blood at the time of her breast cancer diagnosis and her prognosis (how well she does after the diagnosis), including measurements of breast cancer stage and survival.

Study findings:

1. Women with the highest levels of vitamin D (slightly higher than the recommended level) in their blood had better overall survival than women with lower vitamin D levels.
2. Lower vitamin D levels were associated with a more advanced breast cancer stage at diagnosis.

What does this mean for me?

This study suggests that women who have high vitamin D levels (slightly higher than the level recommended by the National Institute of Health) have better overall survival compared to women with lower levels. These findings agree with several other studies of vitamin D levels and breast cancer survival outcomes. But much more work needs to be done before these findings can be applied to preventing breast cancer or recurrence. This study’s results do not mean that increasing vitamin D consumption after a breast cancer diagnosis will improve patient survival; it just means that patients who had better survival were seen to have higher vitamin D levels. The researchers do not know if better survival is directly related to vitamin D.

Ultimately, vitamin D is very important for all women. It helps calcium absorption in the gut, keeps bones strong, and also aids in some functions of immune function, cell growth, and reduction of inflammation. Vitamin D deficiencies result in diseases that cause weak bones and contribute to osteoporosis, so it is important to maintain adequate levels of vitamin D in our bodies whether or not it affects cancer risk or prognosis. Women concerned about their vitamin D levels should consult with their health care provider who can order blood tests to check their vitamin D levels and advise them if dietary changes or supplements are necessary.

Posted 1/10/17

Share your thoughts on this XRAYS article by taking our brief survey

References

Dietary Supplements

National Comprehensive Cancer Network (NCCN) guidelines on survivorship include the following recommendations on dietary supplement use:

- Taking dietary supplements is not recommended for most cancer survivors unless a patient has a known nutritional deficit, an inadequate diet or other indication (for example, osteoporosis).
- Little data exist to support the use of vitamins or other dietary supplements for the purposes of cancer control, recurrence or prevention.
- Taking vitamin supplements does not replace the need for a healthy diet. Patients should try to get nutrients from the foods they eat and the beverages they drink.
- Providers should ask about supplement use at regular intervals, about a patient’s reasons for using supplements and the ingredients in those supplements.
- Survivors of certain cancers are at risk of vitamin deficiencies based on cancer treatment (e.g., gastric cancer patients who have had a gastrectomy may be at risk of vitamin B12 and iron deficiencies).
- NCCN recommends calcium and vitamin D supplements for people who have been prescribed denosumab or a bisphosphonate to treat bone metastasis or osteoporosis.
- Patients taking multiple supplements and those in need of nutritional support should be referred to a registered dietitian or nutritionist, preferably one trained in supporting oncology patients.

Updated: 02/06/2022

Questions to Ask Your Doctor

- Should I have my vitamin D levels monitored?
- If I am vitamin D deficient, what can I do?
- What are measures I can take to reduce my breast cancer risk?
- Should I be taking any other supplements?
- Can you refer me to a nutritionist?
WHO COVERED THIS STUDY?

**Medical News Today**
*Vitamin D may increase survival for breast cancer patients* ★★★★☆☆☆

**New York Times**
*Vitamin D linked to longer breast cancer survival* ★★★☆☆☆☆

**Medical Daily**
*Breast cancer treatment: High levels of vitamin D linked to better prognosis* ★★★☆☆☆☆

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**IN-DEPTH REVIEW OF RESEARCH**

**Study background:**
Previous studies have tried to determine whether there are potential associations between vitamin D levels in the blood and breast cancer risk, but have concluded with mixed results: some say there is an association while others say there is not. But fewer studies have looked at whether there is an association between vitamin D blood levels at the time of diagnosis and breast cancer prognosis; studies that did involve this relationship assessed overall survival, but not deaths from breast cancer. As vitamin D deficiencies have known effects beyond any role in breast cancer, lower overall survival in women with low blood levels of vitamin D may be due to causes unrelated to their breast cancer.

Song Yao and colleagues from the Department of Cancer Prevention and Control at the Rosewell Park Cancer Institute performed a prospective study (meaning they designed the study and collected the data themselves rather than looking back on information collected by others or relying on patients’ recollections). They looked at the association between blood vitamin D levels at the time of diagnosis and breast cancer prognosis.

**Researchers of this study wanted to know:**
Does a woman’s amount of vitamin D in her blood indicate how well she will do after a breast cancer diagnosis?

**Population(s) looked at in the study:**
This study (called the Pathways Study) included 1,666 women who were diagnosed with invasive breast cancer. This population was established at Kaiser Permanente Northern California and was designed to specifically study factors that are associated with breast cancer recurrence and survival. The women’s vitamin D levels were measured shortly after diagnosis and were then followed for up to 96 months after they were enrolled in the study in which researchers tracked participants’ health outcomes.

Vitamin D has several forms in the blood. In this study, the researchers measured a form called 25-hydroxyvitamin D, which according to the National Institutes of Health (NIH) is the best indicator of a person’s overall vitamin D status.
The NIH states that a vitamin D level of 20 ng/mL or greater is considered adequate for bone and overall health. For this study, the researchers divided the women into three groups based on their vitamin D blood levels:

- Group 1 had low vitamin D levels: below 16.75 ng/mL
- Group 2 had vitamin D levels just over or under the recommended levels: 16.75-25.09 ng/mL
- Group 3 had high vitamin levels: 25.10 ng/mL or greater

**Study findings:**

1. Women with the highest level of vitamin D (slightly higher than the recommended vitamin D levels) in their blood had better overall survival than women with lower vitamin D levels.
   - This association was greatest in premenopausal women.
2. Premenopausal women with the highest vitamin D levels were less likely to die from breast cancer within the period of the study than women with lower vitamin D levels.
3. Premenopausal women with the highest vitamin D levels had greater invasive disease-free survival, which included recurrences and secondary cancer diagnoses, than women with lower vitamin D levels.
4. Lower vitamin D levels were associated with a more advanced stage of breast cancer at diagnosis.

**Limitations:**

It is important to understand that the link identified in this study between high vitamin D levels in the blood and better breast cancer survival after diagnosis does not necessarily mean that vitamin D directly caused the better prognosis or that having higher levels of vitamin D in the blood prevents breast cancer diagnosis or recurrence. Other factors that were not measured by the study may have played a role in the women's improved survival.

**Conclusions:**

This study suggests that women who are diagnosed with breast cancer and have high levels of vitamin D have a better prognosis than women with lower levels of vitamin D. More work needs to be done to further understand how this can help women with breast cancer in the clinic. In the meantime, women should maintain a healthy vitamin D level, which benefits their overall health.

Posted 1/10/17

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/vitamin-d-and-prognosis).
Study: Women with breast cancer symptoms but no lump may wait longer to seek medical care

SUMMARY

Some patients take longer than others before getting a potential breast cancer checked by their health care provider. Believing that women who have breast cancer symptoms but have no lump may wait longer, researchers in this study used data from women who were diagnosed with breast cancer in 2009 and 2010 to identify possible explanations. (1/18/17)
Why is this study important?

A breast lump is not the only symptom of breast cancer, but it is the most common. If people are less aware of other breast cancer symptoms, they might delay going to their health care provider, but early diagnosis is important for all breast cancer patients because it increases the chance of survival.

Study findings:

1. About 1 of 6 breast cancer patients went to their health care provider with a symptom other than a breast lump.
2. Breast cancer patients who had symptoms but no breast lump took longer to have their health care provider check their breasts than women whose only symptom was a breast lump.

What does this mean for me?

In a press release, Dr. Karen Kennedy, Director of the National Cancer Research Institute in the United Kingdom (NCRI), said, “This research shows that, all too often, women are delaying going to their doctor with symptoms of breast cancer. This could be because people are simply unaware that breast cancer can present in many different ways, not just through the presence of a lump. With a disease like breast cancer, it’s essential to be diagnosed as early as possible so that a treatment plan can be developed and started. Awareness campaigns need to raise awareness of all of the potential symptoms of breast cancer so that people know how to spot the signs and when to go to a doctor.”

While a breast lump is the most common symptom of breast cancer, many other symptoms should also be checked. According to the American Cancer Society (ACS), other symptoms may include:

- Breast swelling, with or without a lump
- Skin irritation
- Skin dimpling
- Breast or nipple pain
- Nipple turning inward (retraction)
- Redness, scaliness, or thickening of the nipple or breast skin
- Nipple discharge
- Lump or swelling under the arm or around the collarbone

While these symptoms do not necessarily mean a person has breast cancer, people who experience any of them should quickly seek help from a health care provider to identify the cause. It is also important to note that although breast cancer is not usually painful, even painful lumps should be checked out by a health care provider.
What are the symptoms of breast cancer?

Should I be doing breast self exams? How frequently should I check my breasts?

Should a doctor be checking my breasts for lumps? Is so, how frequently?

What changes in my breast should I look for if I am concerned about breast cancer?

Given my family history, how often should I be screened for breast cancer?

**WHO COVERED THIS STUDY?**

- *Breast cancer: The first sign isn't always a lump* ★★★★★
- *Medical Daily*
  - *Breast cancer symptoms: Signs other than lumps lead to detection In five of six cases* ★★★★★
  - How we rated the media
IN DEPTH REVIEW OF RESEARCH

Study background:
The study authors noted that some women take longer than others to get their breast cancer symptoms checked. Minjoung Koo and colleagues from University College London (UCL) presented work at the 2016 National Cancer Research Institute (NCRI) cancer conference in Liverpool that tried to explain why some breast cancer patients took longer to report breast cancer symptoms to their health care providers and ultimately be diagnosed.

Researchers of this study wanted to know:
Could having symptoms other than a breast lump explain why some women take longer to consult with their healthcare provider?

Population(s) looked at in the study:
Data from 2,316 women with breast cancer who were diagnosed in 2009 and 2010 were used for this study. This data included the symptoms present at breast cancer diagnosis.

Study findings:
1. About 1 of 6 breast cancer patients went to their health care provider with a breast cancer symptom other than a breast lump.
2. Compared to women whose only symptom was a breast lump, women who had breast cancer symptoms but no lump waited longer before having their health care provider check their breasts.

Limitations:
This is a retrospective study, meaning the authors used data from previously documented records of patients instead of collecting patient data specifically for this study. This means that other unknown factors may have affected the results. Also, the work was done in England, so factors such as type of health insurance that may have affected access to care in the United States were not addressed. Additionally, because this research has not been published in a peer-reviewed journal, other researchers in the field who can carefully examine the data and confirm the validity of the work have not reviewed it. Finally, while the data indicates that breast cancer patients who had symptoms other than a lump took longer to go to their health care provider, researchers do not know why this occurred, because they were unable to interview or question patients.

Conclusions:
This study suggests that having breast cancer symptoms other than a lump may be one reason why some patients with breast cancer take longer to be diagnosed than others. However, more work needs to be done to understand if that truly is the reason why these patients delayed going to their health care provider. In the meantime, health care providers should be sure to educate patients about non-lump symptoms so that patients can be aware of them and go to their health care provider when any of these symptoms arise.

Posted 1/18/17

Share your thoughts on this XRAYS article by taking our brief survey.
Study: Does prior antidepressant use affect the treatment breast cancer patients receive?

SUMMARY

Previous research found an association between depression and survival in breast cancer patients, but the reasons for this association are unclear. Researchers in this study found that women who had been previously prescribed antidepressants were less likely to receive breast cancer treatment that followed national guidelines than those who had not. Although the difference was small, it underscores the need for patients to discuss any history of depression with their health care providers.

(1/24/17)

STUDY AT A GLANCE

This study is about:

Whether women with a history of depression before their initial early-stage breast cancer diagnosis are more likely to have breast cancer treatment that does not follow national guidelines and also whether they have poorer survival compared to women without a history of depression.
Why is this study important?
To identify groups of patients who may not be getting standard of care treatment that improves their chances of surviving breast cancer.

Study findings:
1. Women from Denmark who were diagnosed with primary early-stage breast cancer and had a history of depression that was treated with antidepressants had increased risk of:
   - receiving breast cancer treatment that did not follow national guidelines.
   - having worse overall survival.
2. While these risks were increased, the overall differences were small between women who were treated with antidepressants and those who were not.

What does this mean for me?
This study suggests that women who had early-stage breast cancer diagnoses and previous treatment for depression were more likely have cancer treatments that did not adhere to national guidelines and also have worse overall survival. A serious limitation of the study is that it could not address why these treatments did not follow national guidelines. While more work needs to be done to understand why this may be occurring, all breast cancer patients should feel comfortable asking their health care providers about their treatments, so that they can understand the reasons for the treatment and any other available options. Oncologists recommend breast cancer treatment based on many different pieces of information, including cancer stage, subtype of breast cancer (e.g. triple-negative breast cancer, ER/PR-positive, HER2-positive, etc.), and sometimes the results of prognostic tests or testing for inherited mutations in BRCA or other genes that increase cancer risk. In the United States, the National Comprehensive Cancer Network publishes versions of the national breast cancer treatment guidelines to help patients understand the current standard of care treatments and facilitate shared decision making with their physicians.

This is an interesting study that generates ideas for further research, but it should not cause alarm for patients who face both depression and cancer. People who are being actively treated for depression at the time of a cancer diagnosis or who have a history of depression should let their oncologists and other health care providers know so that their physicians can provide appropriate care or referrals. Everyone should inform their health care provider of all medications and supplements they are taking.

Posted 1/24/17

Share your thoughts on this XRAYS article by taking our brief survey

References

https://www.facingourrisk.org/XRAY/antidepressants-breast-cancer

Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

Questions to Ask Your Doctor

- What treatments are available to treat my breast cancer?
- Do I need chemotherapy?
- How does depression affect breast cancer?
- I take medication to treat depression. Can I continue during cancer treatment?
- I have struggled with depression in the past. Are there resources for cancer patients dealing with depression?

Open Clinical Trials

The following studies on the emotional effects of cancer are enrolling patients:

Multiple cancers

- NCT04739696: Developing a Virtual Stress Management Intervention for Spousal/Partnered Caregivers of Solid Tumor Cancer Patients. This study will look at the ability of a stress management program for employed caregivers to improve psychological distress in spouses or partners who are caregivers for people diagnosis with a solid tumor cancer of any stage.

- NCT03581357: Mobile Mindfulness Meditation Intervention for Cancer Survivors. This will study the impact and satisfaction of Mobile Mindfulness Meditation on anxiety, pain, fatigue, trauma, and sleep in cancer survivors.

- NCT03611309: Perioperative Palliative Care (PERIOP-PC). The study goal is to compare surgeon-palliative care team co-management, versus surgeon alone management, of patients and family members preparing for major upper gastrointestinal cancer surgery.

- NCT03360695: Bridge: Proactive Psychiatry Consultation and Case Management for Patients With Cancer who have Serious Mental Illness. It is challenging to cope with cancer. The investigators want to understand if it is helpful for patients with serious mental illness (SMI) to be connected to a psychiatrist and case manager when cancer is diagnosed.
The following organizations have resources related to mental and emotional health after a cancer diagnosis.

- FORCE related resources:
  - Information: Emotional wellbeing
  - XRAY category: Emotional health
- National Comprehensive Cancer Network information: Distress During Cancer Care
- Cancer Support Community
- CancerCare
- Cancer Hope Network

Updated: 12/06/2021

WHO COVERED THIS STUDY?

**Rueeters**
Also published in:
The same article was also covered by Fox News.

Past depression tied to worse breast cancer survival odds ★★★☆☆☆☆

**HealthDay**

Depressed women less likely to get best breast cancer care: study ★★★☆☆☆☆

**Oncology Nurse Advisor**

Depression may contribute to receipt of inappropriate breast cancer treatment ★★★★☆☆☆☆

How we rated the media

IN DEPTH REVIEW OF RESEARCH

**Study background:**
Previous studies found an association between depression and survival after breast cancer, with people who have a history of depression experiencing worse rates of survival than those who do not. Nis Suppli and colleagues from the Danish Cancer Society Research Center published work in the Journal of Clinical Oncology in January 2017 to try to understand this association.

Researchers of this study wanted to know:
Do women who have previously been prescribed antidepressants receive different breast cancer treatments than women who have not taken antidepressants?

Population(s) looked at in the study:
This study included 45,325 women from Denmark who were diagnosed with early-stage breast cancer between April 1998 through December 2011: 6,068 (13%) of the women had previously used antidepressants. Women with a previous cancer diagnosis or other major psychiatric disorders were excluded. The study authors used national cancer treatment guidelines and clinical data from the Danish Breast Cancer Group. Information on which women had been prescribed antidepressants was retrieved from the Danish Psychiatric Central Research Register.

Study findings:
1. Women in Denmark who were diagnosed with early-stage breast cancer and who had previously taken antidepressants had increased risk of:
   - receiving cancer treatment that did not follow national guidelines.
   - having worse overall survival.
   - having worse breast cancer-specific survival.
   - While these risks were increased, the overall differences were small between women who were treated with antidepressants and those who had not.

Limitations:
Because the researchers used existing data from registries and did not collect it themselves, they were unable to differentiate between women who had undiagnosed or untreated depression and those who had depression but only had psychotherapy without antidepressants. (The registry information was collected over a 13½-year period during which treatment for both breast cancer and depression has evolved.) Nor did researchers take into account lifestyle factors such as alcohol use, smoking, and access to care. Another problem was the use of antidepressant prescriptions as a measure of the women with depression—this number could include patients who didn’t necessarily have depression, as antidepressants are often prescribed to treat anxiety, pain and other conditions; the number may have also missed people with depression who chose to treat it with other methods. Finally, because of the study design, researchers were unable to understand why treatment for patients who had been prescribed antidepressants was less likely to follow recommended national guidelines. Several reasons are possible, including patient preference, health care providers not offering guideline-based treatments, patients may not have been compliant, or a combination of these and/or other reasons.

It is also important to note that this study was conducted in the Danish health care system and does not necessarily reflect what is happening in the United States.

Conclusions:
This study suggests that early-stage breast cancer patients who were previously treated for depression are more likely to receive cancer treatment other than treatment that is recommended by national guidelines. This is an interesting study that generates ideas for further research, but it should not cause alarm for patients who face both depression and cancer. Breast cancer patients or survivors with depression or a history of depression should discuss any concerns with their health care providers.

Posted 1/24/17

Share your thoughts on this XRAYS article by taking our brief survey
Study: “Chemobrain” seen in breast cancer patients up to six months after treatment

SUMMARY

Many people report memory or concentration problems, commonly known as “chemobrain,” during and after cancer treatment. New research shows that for some breast cancer patients these issues continue 6 months after treatment. Documentation of this well-known effect is a crucial first step in developing ways to limit and treat it. (02/02/17)

This article is relevant for:
- People diagnosed with breast cancer who have or will be treated with chemotherapy

This article is also relevant for:
- Breast cancer survivors

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This study attempted to determine the percentage of breast cancer patients who experience cognitive issues after receiving chemotherapy and how long it lasts, so that health care providers can help patients cope with this effect.

**Study findings:**

1. More than one-third (37%) of breast cancer patients who have had chemotherapy report cognitive difficulties 6 months after treatment.

**What does this mean for me?**

This study suggests that a large number of breast cancer patients who undergo chemotherapy may experience more cognitive difficulties, such as forgetfulness and problems with concentration, than people who are not treated with chemotherapy. This “chemobrain” effect can continue up to 6 months after chemotherapy has been completed. More work needs to be done to understand why this occurs and to identify ways to help patients who experience these difficulties. Patients should talk to their health care providers about this and any other symptoms they have after chemotherapy.

Posted 2/2/17

Share your thoughts on this XRAYS article by taking our brief survey.

**References**


**FACIT Measurement System Questionnaires**

Is my treatment likely to affect my memory?

Will these effects improve over time?

People have been commenting that I am slower/forgetful. Is this because of the chemotherapy?

Is there anything that I can do to improve my memory?

Are there any medications that I can take to improve my memory?

What other treatment side effects should I expect?

The following studies are looking at management of treatment side effects:

**Multiple cancers**

https://www.facingourrisk.org/XRAY/chemobrain
The following organizations have resources related to treatment side effects.

- **FORCE related resources:**
  - Information: [Chemotherapy side effects](#)
  - Information: [Hormone therapy side effects](#)
  - Information: [Immunotherapy side effects](#)
  - Information: [Radiation side effects](#)
  - Information: [Surgery side effects](#)
  - Information: [Targeted therapy side effects](#)
  - Information: [Wellbeing and survivorship](#)
- **XRAY category:** Side effects
- FDA MedWatch [online side effect reporting form](#)
- National Cancer Institute [page on cancer treatment side effects](#)
- Centers for Disease Control [page on cancer treatment side effects](#)
- HairToStay helps cancer patients cover the cost of scalp cooling.
- Unite for Her provides financial support for services that help improve quality-of-life in people diagnosed with breast or ovarian cancer.

Updated: 12/03/2021

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**WHO COVERED THIS STUDY?**

**HealthDay**
Also published in:
The same article was also covered by the [Chicago Tribune](#)

*Chemo brain* lasts for months in many breast cancer survivors ⭐⭐⭐⭐⭐

**Medical News Today**

*Breast cancer patients report *chemo brain* is a substantial problem ⭐⭐⭐⭐⭐⭐

**PsychCentral**

*Chemo-brain may be pervasive in breast cancer patients* ⭐⭐⭐⭐⭐

How we rated the media

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**IN-DEPTH (click to expand)**
IN DEPTH REVIEW OF RESEARCH

Study background:
Researchers are beginning to study cancer-related cognitive impairment, commonly referred to as “chemobrain,” in patients with breast cancer. Early studies were small, included different patient populations (for example, patients with different cancers and treatments), could not be applied to a broad population, or did not study the patients for a long period. Michelle Jansens and colleagues from the University of Rochester Medical Center and other institutions published work in the Journal of Clinical Oncology in December 2016 describing their efforts to try to understand breast cancer patients’ cognitive difficulties after chemotherapy.

Researchers of this study wanted to know:
Do breast cancer patients experience cognitive difficulties after undergoing chemotherapy?

Population(s) looked at in the study:
This study included 581 women from the research base of the National Cancer Institute Community Oncology Research Program (NCORP) at the University of Rochester. The data represented women who:

- had invasive breast cancer (stages I-III).
- were scheduled to begin chemotherapy (but not radiation at the same time).
- did not have metastatic disease.
- did not previously have chemotherapy.
- were 21-years-old or older.

The study also included 364 women without cancer who were also recruited by the NCORP. This population included friends and family of the study participants and people who had no relationship with patients in the study.

All participants took the FACT-Cog survey, which addresses the following general areas:

- Perceived cognitive impairment ("I have had trouble concentrating, I have forgotten names of people soon after being introduced," etc.)
- Perceived cognitive abilities ("My memory is as good as it has always been," etc.)
- Impact of cognitive impairment on quality of life ("These things have interfered with my ability to do things I enjoy," etc.)
- Cognitive impairment perceived by others ("Other people have told me I seemed to have trouble remembering information," etc.)

Patients took this survey before chemotherapy, within four weeks of receiving chemotherapy, and six months after chemotherapy. Non-cancer patients were surveyed during the same period.

Study findings:
1. Breast cancer patients who have had chemotherapy are more likely to report cognitive difficulties, as measured by the FACT-Cog survey (which includes questions about patients’ forgetfulness, concentration, memory, quality of life, and any “chemobrain” identified by others):
   - 45% of breast cancer patients reported cognitive difficulties within 4 weeks of receiving treatment, compared to only 10% of people without cancer.
   - 37% of breast cancer patients reported cognitive difficulties 6 months after chemotherapy treatment,
compared to 14% of people without cancer.

Limitations:
The follow-up period of this study was only six months, so it is not known if these symptoms linger even longer in some patients. However, to address this limitation, the researchers report that they are currently observing a small group of breast cancer patients and people without cancer for two years post treatment.

Additionally, in this study breast cancer patients undergoing chemotherapy were compared to women who did not have cancer, so it is not clear whether the memory issues are caused by the stress of facing cancer and its treatment in general or something specific to chemotherapy. Additionally, more work needs to be done to understand how anxiety, depression and other factors affect cognitive function in this population.

Conclusions:
This study suggests that nearly half of breast cancer patients who undergo chemotherapy treatment experience cognitive difficulties ("chemobrain"), with just over one-third of patients reporting symptoms even 6 months after treatment. More work needs to be done to understand why these patients experience "chemobrain," if this is a long-term effect, and potential ways to prevent "chemobrain" or to help patients who experience it. Meanwhile, patients should discuss any cognitive problems or other symptoms they experience after chemotherapy with their health care providers.

Posted 2/2/17

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☐ - Basic Science
☐ - Cancer Diagnosis
☐ - Cancer Risk
☐ - Cancer Treatment
☐ - Clinical Trials
☐ - Emotional Health

https://www.facingourrisk.org/XRAY/chemobrain
Study: A step in the development of a new breast cancer risk assessment tool for Hispanic women

SUMMARY

Current tools used to calculate breast cancer risk make their estimations based on data from non-Hispanic white women and may not accurately predict breast cancer risk in women of other races and ethnicities. With further testing, a new risk assessment tool developed specifically for Hispanic women could more accurately predict breast cancer risk in women who do not have mutations in BRCA or other genes associated with hereditary breast cancer. (02/07/17)
The current risk calculation tool used to predict the likelihood of breast cancer underestimates the risk in Hispanic women by 18%, most likely because it combines data from Hispanic women and non-Hispanic white women. Models based on data from other races and ethnicities are needed to provide more accurate risk estimates for non-white populations.

**Study findings:**

1. The researchers developed a new risk assessment tool (the Hispanic risk model) that only includes data from Hispanic women.

**What does this mean for me?**

Researchers of the current study have developed a new risk assessment tool to estimate the absolute risk of invasive breast cancer for Hispanic women. However, much more work needs to be done to evaluate the validity of this tool. Hispanic women should speak to their health care providers with any concerns they may have about their breast cancer risk. All women, regardless of their race or ethnicity, who have breast cancer before age 50, triple-negative breast cancer at any age or ovarian cancer at any age meet national guidelines for genetic testing for mutations in BRCA or other genes that increase cancer risk. Women who do not have cancer but who have a strong family history of breast or ovarian cancer should talk to their health care providers to see whether genetic counseling is right for them.

Posted 2/7/17

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**References**

The following organizations have resources related to cancer disparities.

- FORCE health disparities resources:
  - Blogs: [Health Equity](#)
  - XRAY review: [Breast cancer disparities in Black Americans](#)
  - XRAY category: [Racial and ethnic differences](#)
  - Video: [I'm Not White, Can I Still Have a Mutation?](#)
  - Video: [In Our Voices: Asian American Experiences with Genetic Counseling for Hereditary Cancer](#)
  - Video: [Black Men: Overcoming Prostate Cancer Disparities through Screening, Prevention & Genetics](#)
  - Personalized portal: [Information in Spanish](#)
  - [AACR Healthcare Disparities Progress Report 2020](#)
  - [Asian Pacific Partners for Empowerment, Advocacy and Leadership (APPEAL)](#)
  - [Black Health Matters](#)
  - [For the Breast of Us](#)
  - [National Alliance for Hispanic Health](#)
  - [National LGBT Cancer Network](#)
  - [Tigerlily Foundation](#)

Updated: 11/22/2021

**WHO COVERED THIS STUDY?**

**UPI**

New breast cancer model developed for Hispanic women ★★★★☆☆☆☆

**Healio, HemOnctoday**

New breast cancer model designed to predict risk in Hispanic women ★★★★☆☆☆☆

How we rated the media

**IN DEPTH REVIEW OF RESEARCH**

Study background:
The National Cancer Institute’s Breast Cancer Risk Assessment Tool (BCRAT) is currently used to predict breast cancer risk in women who do not have mutations in BRCA or other genes associated with hereditary breast cancer. However, for Hispanic women, the BCRAT develops estimates of invasive breast cancer risk by combining Hispanic age-specific incidence rates with relative risks from white women. A previous research study reported that BCRAT underestimates Hispanic women’s breast cancer risk by 18%.

Matthew Banegas and colleagues from Kaiser Permanente Northwest published work in the Journal of the National Cancer Institute describing their new breast cancer risk estimation tool developed specifically for Hispanic women.

**Researchers of this study wanted to:**

Develop a risk assessment tool for calculating breast cancer risk specifically for Hispanic women.

**Population(s) looked at in the study:**

The researchers used data from the following sources for their model:

- The San Francisco Bay Area Breast Cancer Study (SFBCS) included Hispanic women, ages 35-79 who were diagnosed with a first primary invasive breast cancer between 1995 and 2002. The study included information from 1,086 women with invasive breast cancer (533 were US-born while 553 were foreign-born) and 1,411 control participants (464 were US-born while 947 were foreign-born).
- The California Cancer Registry (CCR) and SEER program were used for additional incidence and mortality information.

The risk estimates from the researchers’ new model were compared to the estimates from the National Cancer Institute’s Breast Cancer Risk Assessment Tool (BCRAT).

**Results**

1. The researchers developed the Hispanic Risk Model (HRM) to estimate breast cancer risk that only uses data from Hispanic women.

   - The risk factors incorporated in this model included age at first full-term pregnancy and family history of breast cancer in first-degree female relatives.
   - Breast cancer risk calculated by the HRM was lower than the risk calculated by the National Cancer Institute’s Breast Cancer Risk Assessment Tool (BCRAT) for Hispanic women who were born in the U.S., but it was higher for foreign-born Hispanic women.

**Limitations:**

The researchers’ risk tool only used data from Hispanic females residing in California, so it is unknown how the tool will perform with other populations. And while different Hispanic subgroups exist in the United States, including women with different countries of origin as well as different races, the researchers categorized all Hispanic women into one group. Additionally, the San Francisco Bay Area Breast Cancer Study (SFBCS) group included only women who were 35-79 years old.

In addition, not all risk factors were accounted for in the researchers’ model, such as breast density and genetic variants. Additional factors could refine the model so that it accurately predicts breast cancer risk in both Hispanic women born in the United States and those born overseas. Finally, the researchers wrote that “The HRM, like the BCRAT, should not be used for certain women. It will probably underestimate breast cancer risk in Hispanic women with a personal history of breast cancer..., in women carrying breast cancer-causing mutations, and in women who received therapeutic radiation doses to the breast at a young age, such as for treatment of Hodgkin’s lymphoma.”
**Conclusions:**

Researchers have developed a new risk assessment tool to calculate breast cancer risk in Hispanic women who do carry gene mutations associated with hereditary breast cancer. Like the currently used BCRAT model, this model looks at risk for invasive breast cancer (stages I-IV) and not ductal carcinoma in situ (DCIS or stage I 0). However, more work needs to be done to validate this new model. In the meantime, Hispanic women should discuss any concerns they have with their health care providers.

Posted 2/7/17

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**SEARCH XRAY STUDIES AND ARTICLES**

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**Categories:**

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
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- Emotional Health
- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing
- Health Disparities
- Health Literacy
- Hereditary Cancer
- Intimacy & Body Image
- LGBTQIA+
- Male Breast Cancer
- Menopause
- Metastatic Cancer

Can a chemical found in hot chili peppers someday be used to treat breast cancer?

Study: Hot chili pepper component slows growth and kills laboratory-grown breast cancer cells

**Summary**

Finding new treatments that target triple-negative breast cancer is an area of great interest. An early step in developing these treatments is learning more about the biology of tumor in the laboratory. This study looked at how capsaicin, the spicy component of chili peppers, might work with a protein found in many cancers, including triple-negative breast cancer, to stop cancer cell growth. This is the first step in a long process towards developing new treatments for triple-negative breast cancer. (2/14/17)

This article is relevant for:
- This research is not relevant to people yet

This article is also relevant for:
- Men with breast cancer
- Metastatic cancer
- Triple negative breast cancer
- Women under 45
Can a chemical found in hot chili peppers someday be used to treat breast cancer?

Why is this study important?
Preliminary laboratory studies like these are important because they help researchers to understand how breast cancer cells differ from normal cells and to identify new drugs to treat the cancer.

Study findings:
1. TRPV1, a protein that has been shown to be involved in cancer growth, was found in 49 different breast cancer cells grown in the laboratory and in 11 tumor samples from breast cancer patients.
2. Triple-negative breast cancer samples had the most TRPV1 protein.
3. Capsaicin, the spicy component of chili peppers, worked with TRPV1 protein in the laboratory grown triple-negative breast cancer cells to restrict their growth and cause them to die.

What does this mean for me?
This is very early research that could lead to new treatments. Laboratory studies like this one must be confirmed by more research and then tested in patients through clinical trials before they become part of recommended treatment. This study does not mean that chili peppers prevent or help treat cancer.

While this study is not ready for clinical trials, many open trials are studying ways to treat all stages of triple-negative breast cancer. For now, patients with triple-negative breast cancer should talk to their health care providers about treatment options and discuss whether or not a clinical trial is a good option. In addition, all women with triple-negative breast cancer before age 60 meet national guidelines for genetic counseling and testing for mutations in BRCA() or other genes that increase cancer risk.

Posted 2/14/17

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References


Disclosure
FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAY articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
Can a chemical found in hot chili peppers someday be used to treat breast cancer?  

WHO COVERED THIS STUDY?

Mirror
Chillies could help beat cancer as research finds capsaicin destroys diseased cells

Medical News Today
Chili pepper compound can stop breast cancer, study finds

Daily Mail UK
Hot off the press! How the spicy kick in CHILLIES can ‘help destroy cancer cells by making them self-destruct’

Newsmax
Chili peppers inhibit cancer growth

University Herald
How eating curry can help kill breast cancer cells

Yahoo News
Spicy foods might hold the key to a breast cancer cure

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
The TRPV1 protein detects harmful heat and helps pathways in your body to control pain relating to temperature changes. Extremely hot temperatures, acidic conditions and capsaicin, the spicy component of chili peppers, activate TRPV1. Previous researchers found that TRPV1 is involved in the growth of cancers, such as colon and pancreatic. However, it has not been studied as much in breast cancer, and its role in all of these cancers is not well understood.

Lea Weber and colleagues from Ruhr University Bochum and other institutions published work in the journal Breast Cancer: Targets and Therapy in December 2016 to try and understand if and how TRPV1 protein is involved in breast cancer.

Researchers of this study wanted to know:
Is TRPV1 involved in breast cancer?

Population(s) looked at in the study:
This study included tumors from 11 different breast cancer patients and 49 different types of breast cancer cells grown in the laboratory.

https://www.facingourrisk.org/XRAY/hot-chili-pepper
Study findings:

1. TRPV1, a protein that has been shown to be involved in cancer growth, was found in 49 different breast cancer cells grown in the laboratory and 11 tumor samples from breast cancer patients.

2. Triple-negative breast cancer samples had the most TRPV1 protein.

3. Capsaicin, the spicy component of chili peppers, activates the TRPV1 protein. Adding capsaicin to triple-negative breast cancer cells slowed their growth and caused them to die.

Limitations:

While these findings are interesting, they come from a very early research study. The capsaicin treatment was used on cells grown in the laboratory, not on mice or humans. More work is needed to find out if this treatment works in animal models of breast cancer before it can be tested for human safety and effectiveness. **At this time, we do not know if the lab response would be duplicated in human breast cancer patients.**

It is also critical to understand that this experiment used pure capsaicin, the spicy component of chili peppers, which was likely much stronger than one would consume by eating chili peppers. The research does not show if consuming chili peppers would have any effect. This means that this study **does not** identify capsaicin as an ingredient to help people lower their breast cancer risk, treat breast cancer, or help prevent recurrence.

Conclusions:

This research is an early study that suggests the TRPV1 protein may play a role in breast cancer, especially triple-negative breast cancer, because it was found in all of the breast cancer cells grown in the laboratory and from patient tumor samples. It also showed that adding capsaicin, the spicy component of chili peppers, helped stop the triple-negative breast cancer cells from growing. However, because this is very early research done in cells grown in the laboratory, much more work needs to be done before this can be applied in a health care setting. Women interested in participating in trials looking at new treatments for breast cancer are encouraged to ask their health care providers about clinical trials or visit the Research section of the FORCE website.

Reports of this research have been widely shared on social media. Snopes, a website that validates or debunks news stories, has also stated that the claim that “capsaicin, the spice-causing molecule in chili peppers, can help beat breast cancer,” is unproven.

Posted 2/14/17

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SEARCH XRAY STUDIES AND ARTICLES

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Study: Research suggests exercise is safe for breast cancer patients at risk for lymphedema

SUMMARY

Patients and health care providers are often concerned about how exercise affects lymphedema (swelling in the arm or hand) in breast cancer survivors or other women who have had lymph node biopsy at the time of mastectomy. Research on this topic has been mixed. A new study suggests that exercise after breast cancer treatment does not lead to lymphedema or worsen existing lymphedema. However, because this study was small, more work needs to be done to understand the relationship between exercise and lymphedema in cancer survivors. (2/22/17)

STUDY AT A GLANCE

This study is about:

How exercise affects lymphedema (swelling in the arm or hand) that can occur after breast cancer treatment.

Why is this study important?

Over the years, research on the relationship of exercise to lymphedema has had mixed results; some studies suggested that exercise could cause cancer patients to develop lymphedema or make their current lymphedema worse.
while other studies found that a gradual exercise program helps patients with lymphedema.

**Study findings:**

After 6 months of resistance exercise training, the extent of lymphedema did not change significantly.

**What does this mean for me?**

This study suggests that women who have been treated for breast cancer can perform moderate-intensity exercise (including aerobic and strength exercises) without developing lymphedema or making their existing lymphedema worse. However, as other research studies in the literature contradict these findings, more work is needed to fully understand the relationship between exercise and lymphedema development. **Breast cancer survivors and women who have had mastectomy should report any symptoms of lymphedema to their health care providers, and consult with them before beginning any type of exercise program.**

Posted 2/22/17

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/exercise-and-lymphedema)

**References**


WHO COVERED THIS STUDY?

HealthDay
Strength training may prevent side effect of breast cancer surgery ★ ★ ★ ★ ★

Practical Pain Management
Weight training beneficial for breast cancer survivors ★ ★ ★ ★ ★

CURE
Breast cancer survivors may knock out lymphedema by weightlifting ★ ★ ★ ★ ★

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Lymphedema, a swelling of the arm or hand due to lymph node damage, is an adverse side effect that often occurs after breast cancer treatment. Currently there is no cure for lymphedema. Patients who develop this condition can ultimately experience symptoms such as changes in sensation in the arms, a greater feeling of fatigue, and decreased quality of life. Other side effects of breast cancer treatment include decreased bone health and increased fat mass. Strength or resistance exercises can help patients to improve their bone health and weight gain that may occur. However, some research suggests that resistance exercise may cause patients to develop lymphedema or make it worse.

Emily Simonavice and colleagues from the School of Health and Human Performance in George College and State University and other institutions studied the effect of resistance exercise in women who were treated for breast cancer; their results were published in the journal Supportive Cancer Care. This is one of several recent studies that suggests that strength exercise is safe for breast cancer survivors and does not cause lymphedema or make existing lymphedema worse.

Researchers of this study wanted to know:
How does exercise affect lymphedema in women who have been treated for breast cancer?

Population(s) looked at in the study:
- Study participants included 25 women who:
  - had breast cancer between stages 0-III
  - completed all primary treatments (surgery, radiation, and/or chemotherapy) at least 6 months before the study started
- Initially, 27 women began the study, but two dropped out due to clinical complications unrelated to lymphedema. However, data from these women while they were in the study were collected and included in the results.
Three of the women already had lymphedema when the study began.

Each woman had 2-hour, moderate resistance exercise training sessions per week, which included an aerobic warm-up and exercises targeting all major muscle groups (such as chest presses, leg presses, biceps curls).

The presence and/or extent of lymphedema was determined by measuring each woman’s arm circumference every two weeks.

Study findings:

1. After 6 months of resistance exercise training the extent of lymphedema did not change significantly.

Limitations:

These findings are preliminary because this study did not include a control group. Although all of the women included in the study performed the moderate resistance training, the researchers could not compare lymphedema between women who did and did not exercise (no information was available regarding the arm circumference changes of breast cancer survivors who did not exercise over the same period). It was also a relatively small study: just 27 women. Additionally, the study included only 3 women who already had lymphedema; too small to generalize the findings to all women with lymphedema. Another reason that this study cannot be generalized is because participants had different combinations of surgery, radiation, chemotherapy, and lymph node dissection (not all women had all four treatments). Finally, the study also looked only at breast cancer survivors. The effects of exercise on previvors after risk-reducing mastectomy due to a mutation in BRCA1 or other gene that affects cancer risk is not addressed by this study.

Conclusions:

This study suggests that women who have been treated for breast cancer can exercise without developing lymphedema or making their lymphedema worse. Because of the study’s limitations, however, more work needs to be done to fully understand the relationship between exercise and lymphedema. Other researchers have explored this area—a 2009 paper in the New England Journal of Medicine by Dr. Kathryn Schmitz from the University of Pennsylvania School of Medicine showed that breast cancer patients with existing lymphedema who did resistance exercise had greater improvements in the severity of their self-reported lymphedema symptoms compared to patients who did not exercise. Another recent report of preliminary findings presented at the Cancer Survivorship Symposium Advancing Care and Research in 2017 found no difference in the rates of lymphedema between breast cancer patients who exercised and those who did not.

All women who undergo breast surgery and/or radiation to treat breast cancer or reduce the risk of breast cancer are at risk for lymphedema; having axillary lymph node dissection increases that risk.

Current breast cancer survivorship care guidelines from the American Cancer Society and the American Society of Clinical Oncology recommend that health care providers refer patients with arm swelling or other symptoms of lymphedema to a lymphedema specialist who can recommend appropriate treatment. These guidelines also note that more research is required to develop clear evidence-based recommendations to prevent lymphedema after breast surgery and/or radiation. Patients concerned about lymphedema should discuss symptoms with their health care providers to determine what treatment or prevention measures are best for them.

Posted 2/22/17

Share your thoughts on this XRAYS article by taking our brief survey.
Study: Patient experiences with genetic testing

**SUMMARY**

Patients can now find out if they have a mutation in more than 20 different genes that are associated with cancer risk, thanks to research advances and the decreasing cost of genetic testing. However, patients’ experiences and use of genetic counseling and testing with these changes are unknown. Do patients want genetic testing? Are they getting tested? (3/7/17)

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This article is relevant for:

- Women diagnosed with early-stage breast cancer

This article is also relevant for:

- Breast cancer survivors
- ER/PR +
- Her2+ breast cancer
- Triple negative breast cancer
- Women under 45
Because of new technology, genetic testing has now become more affordable and easier than ever. Panel testing allows for simultaneous testing of multiple genes from each patient. However, not much is known about patients’ experiences with genetic testing and counseling now that they can have more genes tested at a lower cost.

**Study findings:**

1. Among women who were diagnosed with breast cancer and were at high risk (determined through various criteria including personal and family history of cancer) for carrying a gene mutation that increases cancer risk:
   - about 81% wanted genetic testing
   - about 71% talked about testing with a doctor or other health professional
   - about 40% had genetic counseling
   - about 53% were tested.

2. About 62% of patients who were at high risk for carrying a gene mutation that increases cancer risk and were tested had a session with a genetic counseling expert.

3. About 56% of patients who were at high risk for carrying a gene mutation that increases cancer risk were not tested, reporting that, “my doctor didn’t recommend it.”

**What does this mean for me?**

This study suggests that patients diagnosed with breast cancer want genetic counseling and testing, but due to various reasons, not all patients who meet national guidelines for genetics evaluation are getting these recommended high-risk services. More work is needed to assure that all breast cancer patients who meet national guidelines and want genetic testing have access. **In the meantime, breast cancer patients should talk to their health care providers about genetic counseling and testing.**

Posted 3/7/17

Share your thoughts on this XRAY article by taking [our brief survey](https://www.facingourrisk.org/XRAY/genetic-testing-experiences).

**References**


**Disclosure**

FORCE receives funding from [industry sponsors](https://www.facingourrisk.org/), including companies that manufacture cancer drugs, tests and devices. All XRAY articles are written independently of any sponsor and are reviewed by members of our [Scientific Board](https://www.facingourrisk.org/).
WHO COVERED THIS STUDY?

Washington Post
Many high-risk patients with breast cancer aren’t getting genetic testing. Here’s why.

NPR
Women with breast cancer miss out on recommended genetic testing

Daily Mail
Also published in:
The same article was also covered by Yahoo

Genetic testing often overlooked for cancer risk women: study

Medpage Today
Also published in:

Most women with breast cancer did not get genetic testing

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Genetic testing is becoming increasingly available and more affordable. In the past few years, panel tests identifying mutations in multiple genes that increase a person’s risk for cancer have become widely available. Twenty years ago, genetic testing only identified whether an individual’s DNA had changes in the BRCA genes. Now, panel testing simultaneously searches for mutations in more than 20 different genes that are associated with increased cancer risk. This study looks at breast cancer patients’ experiences with genetic testing in this new environment.

Allison Kurian and colleagues from Stanford University and other institutions published work in the Journal of the American Medical Association in February 2017; they collected data on breast cancer patient preferences and experiences with genetic testing.

Researchers of this study wanted to know:
What are breast cancer patients’ experiences with genetic counseling and testing?

Population(s) looked at in the study:
The study included 2,529 women between the ages of 20 and 79 who were diagnosed with stages 0-II breast cancer between July 2013 and September 2014. These women were identified from the Surveillance Epidemiology and End Results (SEER) data registries from Georgia and Los Angeles County.

Women in the study were mailed surveys that questioned them about:

- how much they wanted genetic testing
- whether they talked about genetic testing with any "doctor or other health professional"
- whether they had a session with a genetic counseling expert
- whether they had genetic testing

Women from this population were categorized as high risk for carrying a mutation in a gene that increases cancer risk if they met one or more of the following criteria:

- Were under 45 years old at breast cancer diagnosis
- Had bilateral breast cancer (breast cancer in both breasts)
- Had triple-negative breast cancer diagnosed at 60 years old or younger
- Had a relative with ovarian cancer, sarcoma, or male breast cancer
- Had 2 or more first-degree relatives with breast cancer
- For patients who were diagnosed at age 50 or younger, those who were classified as high risk or had 1 or more first-degree relatives with breast cancer, Ashkenazi Jewish ancestry, or a family history of a mutation in a BRCA gene or other gene that increases cancer risk

All other women were classified as having an average risk of carrying a mutation in a cancer risk-increasing gene.

**Study findings:**

1. 31% of the total study population were classified as being at high risk for carrying a gene mutation associated with increased cancer risk.

2. Among women who were diagnosed with breast cancer and were at high risk for carrying a gene mutation associated with increased cancer risk:
   - about 81% wanted genetic testing
   - about 71% talked about testing with a doctor or other health professional
   - about 40% had a session with a genetic counseling expert
   - about 53% had genetic testing.

3. Among women who were diagnosed with breast cancer, had a high risk for carrying a gene mutation associated with increased cancer risk, and were tested:
   - about 62% had a session with a genetic counseling expert.

4. Patients who were at high risk for carrying a gene mutation associated with increased cancer risk reported that they did not pursue testing because:
   - "my doctor didn’t recommend it" (about 56%)
   - "too expensive" (about 14%)
"I did want it" (about 11%)

Individuals who were older or of Asian ethnicity were less likely to have genetic testing.

**Limitations:**

Because this study used self-reported survey results, the chance for error and bias exists. Additionally, only patients from Georgia and Los Angeles County were included in this study, so it is unknown if the results can be generalized more broadly. Finally, for the reasons why genetic testing was not pursued, this study only included the patient perspective and did not get the perspective from the healthcare provider.

**Conclusions:**

This study suggests that patients want genetic counseling and testing, but various reasons keep many of them from getting these services. Only 53% of women from this study who were at high risk for carrying a mutation in a gene associated with increased cancer risk had genetic testing. Also of note: only 40% of women at high risk for having a mutation had genetic counseling. More work needs to be done to understand why this occurs and how access to genetic counseling and testing can be improved. Meanwhile, patients who are concerned about carrying a mutation in a gene that increases cancer risk should talk to their healthcare providers and/or a genetics expert.

**Posted 3/7/17**

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/genetic-testing-experiences)

**SEARCH XRAY STUDIES AND ARTICLES**

**Keyword:**

**Cancer Type:**

Choose ▼

**Relevant for:**

Choose Cancer Type First... ▼

**Categories:**

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure
- Family & Caregivers

https://www.facingourrisk.org/XRAY/genetic-testing-experiences
Study: Friends and family may help breast cancer survival

SUMMARY

Does having a large social network help breast cancer survivors have better outcomes? Research from the current study found that socially isolated breast cancer survivors had an increased risk of recurrence and breast cancer-specific mortality. (3/16/17)

STUDY AT A GLANCE

This study is about:
Whether social networks are associated with better survival after breast cancer.

Why is this study important?
If social networks are beneficial to a woman’s prognosis after breast cancer, researchers and health care providers can use this information to develop more effective social and clinical interventions to help survivors.
Study findings:

1. Socially isolated breast cancer survivors had higher risk of recurrence, breast cancer-specific mortality, and overall mortality compared to survivors who had large social networks.

What does this mean for me?

This study suggests that social networks may be beneficial for breast cancer survivors. While researchers and health care providers do not understand exactly how a large social network benefits prognosis and survival, survivors should make sure to reach out to family and friends if they need support and assistance. Additionally, they can reach out to health care providers or find support groups to talk to about their concerns.

Posted 3/16/17

Share your thoughts on this XRAYS article by taking our brief survey.

Reference


Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

Questions to Ask Your Doctor

- What can I do to lower my risk for a recurrence?
- Are in-person or online support groups available for people with a diagnosis similar to mine?
- Can you refer me to palliative care specialist?
- My family member or caregiver is having a difficult time coping with my diagnosis. Are there resources available to help them?
- What supportive services would you recommend for me?
- What are the most trustworthy sites to find information on breast cancer?

The following studies on the emotional effects of cancer are enrolling patients:

Multiple cancers

- NCT04739696: Developing a Virtual Stress Management Intervention for Spousal/Partnered Caregivers of Solid Tumor Cancer Patients. This study will
The following organizations have resources related to mental and emotional health after a cancer diagnosis.

- **FORCE related resources:**
  - Information: [Emotional wellbeing](#)
  - XRAY category: [Emotional health](#)
- **National Comprehensive Cancer Network information:** [Distress During Cancer Care](#)
- **Cancer Support Community**
- **CancerCare**
- **Cancer Hope Network**

Updated: 12/06/2021

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**WHO COVERED THIS STUDY?**

**Medical Xpress**

*Socially isolated breast cancer patients face higher recurrence and mortality rates* ★★★★★★

**Paste**

*Are friends crucial to breast cancer survival?* ★★★★★★

**EmaxHealth**

*Social connections can help women beat breast cancer* ★★★★★★

**How we rated the media**

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**IN DEPTH REVIEW OF RESEARCH**

**Study background:**

Previous work found an association between better overall survival in cancer patients who had good support networks; however, improved breast cancer-specific mortality has not been studied.

Candyce Kroenke and her colleagues from Kaiser Permanente and other institutions published research in 2016 in the journal *Cancer* that studied the association between breast cancer-specific mortality and social networks.

**Researchers of this study wanted to know:**

Does a larger social network help breast cancer survivors have a better prognosis?
Population(s) looked at in the study:
The 9,267 women in this study were part of the After Breast Cancer Pooling Project (ABCPP) and previously had invasive breast cancer (stage I-IV). The ABCPP included women from multiple United States locations and Shanghai, China.

The researchers measured women’s social networks within two years after their diagnosis, using the Berkman-Syme social network index. This index includes five components:

- spouse/intimate partner
- number of relatives
- friendship ties
- religious/social ties
- community ties

A higher number on the index meant that the women had greater social ties.

Depending on her score, each woman’s data was assigned to one of three groups:

- Socially isolated
- Moderately integrated
- Socially integrated

The women were then followed for up to 21 years (the follow-up time for individuals ranged from about 1 to 21 years) to observe rates of recurrence, breast cancer-specific mortality and overall mortality.

Study findings:

1. Socially isolated breast cancer survivors had higher risk of recurrence, breast cancer-specific mortality, and overall mortality compared to survivors who had large social networks.

2. Having no spouse/partner and community ties was associated with higher breast cancer-specific mortality in older white women.

3. Having no relatives or friendship ties was associated with higher breast cancer-specific mortality in nonwhite women.

Limitations:

This study did not include many women of lower socioeconomic status, who tend to have smaller social networks and poorer survival. So while not definitive, it is more likely that because of this limitation, the study underestimated the association between social networks and survival. Nor did this study include many African American or Hispanic women. Finally, the study authors acknowledged that having later stage disease, such as metastatic breast cancer, could be a factor in determining social network size.

Conclusions:

This study suggests that not having a large social network is associated with poorer outcomes after breast cancer, though more work needs to be done to understand why. Women who have had breast cancer should reach out to their family, friends, health care providers, and other support groups if they need support or assistance.

Posted 3/16/17
Article: Huffington Post article brings attention to metastatic breast cancer

SUMMARY

Barbara Jacoby's Huffington Post piece, "How do breast cancer and metastatic breast cancer differ?" emphasizes the need for more treatment options for patients with advanced breast cancer.

Contents

How do early and metastatic breast cancer differ?
Common misconceptions
Why metastatic breast cancer is difficult to treat?

Metastatic Breast Cancer Alliance
Questions for your doctor
Resources and references

What is this article about?

"When breast cancer moves to the brain or bones or lungs or liver, the conception is that you now have brain cancer or bone cancer or lung cancer or liver cancer," writes Barbara Jacoby in her Huffington Post piece, "How do breast cancer and metastatic breast cancer differ?"

This article is relevant for:

- People diagnosed with metastatic breast cancer
- Metastatic cancer

This article is also relevant for:

- Visit our XRAY blog
- Return to XRAY home page
- Suggest an article

Printable PDF

Read the article that we reviewed

Summary

Relevance
October is National Breast Cancer Awareness month, which aims to increase attention and awareness regarding breast cancer. According to the World Health Organization, “When breast cancer is detected early, and if adequate diagnosis and treatment are available, there is a good change that breast cancer can be cured.”

However, Jacoby brings attention to the fact that patients with metastatic breast cancer feel like “the forgotten ones” that “have not been understood and/or heard by the general population.” In her essay, she explains how metastatic breast cancer differs from early breast cancer.

**What is the difference between early breast cancer and metastatic breast cancer?**

Patients with early breast cancer have cancer that stays in the breast or moves to the underarm lymph nodes.

Locally advanced disease is breast cancer that spreads to the chest wall, breast skin or other lymph nodes, like the ones in the breast.

A patient has advanced or metastatic (stage IV) breast cancer when his/her cancer spreads beyond the breast and nearby lymph nodes in the armpit to other organs, such as the lungs, liver, bones, or brain.

**Common misconceptions about metastatic breast cancer**

Some terms used when talking about metastatic breast cancer can be confusing. One common misunderstanding is how to talk about breast cancer after it has spread to other organs. Jacoby points this out in her article, explaining that even when breast cancer spreads to the lungs, liver, or brain, it is still breast cancer, or as she notes, “A cancer is identified by its origin and not by a location to which it has advanced.”

Media reports sometime use the terms “metastasis” and “metastatic cancer” to describe breast cancer that has spread to the lymph nodes. But it is important to remember that metastatic breast cancer has moved beyond the breast and lymph nodes, traveled through the blood stream and/or the lymphatic system to other organs where it continues to grow. Patients who have breast cancer that has progressed to the lymph nodes have cancer that has spread, but it is not metastatic breast cancer.

Although identifying and treating cancer at its earliest stages often prevents it from spreading to other parts of the body, early detection doesn’t guarantee that metastasis won’t occur, or that it hasn’t already occurred at the time of diagnosis. Jacoby notes that some patients are initially diagnosed with metastatic breast cancer.

Finally, Jacoby reminds the reader that not all breast cancers are alike. Just as they differ based on subtype, metastatic breast cancer is different than early breast cancer.

**What are the difficulties in treating metastatic breast cancer?**
Patients’ response to treatment is extremely variable, according to Jacoby. A patient may respond well to a drug for a month, when it then stops working; another patient may never show a positive response to the same drug. Some patients may have minimal side effects while taking a drug while others may have an extremely difficult time with the same drug.

We need good treatment options for all metastatic breast cancer patients; this can only become a reality with increased funding for research that targets metastatic cancer, as well as targeted therapy based on the type of breast cancer and presence or absence of inherited mutations in genes that increase cancer risk.

**Nonprofits and industry working together**

Jacoby’s article spotlights metastatic breast cancer, primarily for the general public. Another effort with similar focus is The Metastatic Breast Cancer Alliance (MBCA). This coalition of nonprofits, includes FORCE, our XRAYS partners (Living Beyond Breast Cancer, Tigerlily, Triple Step Toward the Cure, and the Young Survival Coalition), and industry partners who formed in 2013 to identify and address issues facing people with metastatic breast cancer. In 2014, MBCA published a landscape analysis identifying the need for more funds to be directed to metastatic breast cancer research.

**Highlights of the MBCA findings include:**

- Only 7% of the $15 billion that was invested in breast cancer research from 2000-2013 by major governmental and nonprofit funders from North America and the United Kingdom was dedicated to metastatic breast cancer.

- Breast cancer research is usually performed on tissue taken from patients with early-stage primary breast cancer—not from patients with metastatic breast cancer.

- Not enough funding is allocated toward translational, clinical, or cancer control research for metastatic breast cancer—the majority goes to basic research.

- Basic research needs to uncover all steps in the metastasis, which will help with the development of new treatments.

The MBCA analysis also identified gaps in the understanding of the epidemiology of metastatic breast cancer, including:

- an accurate estimate of how many men and women are living with metastatic breast cancer.

- a better understanding of how many people diagnosed with early-stage breast cancer go on to develop metastatic breast cancer.

- research on how cancer subtypes (Her2+, ER+/PR+, triple negative) affects outcomes for patients with metastatic breast cancer.

- the impact of socioeconomic factors on treatment, care, and quality of
life.

The landscape analysis also looked at the quality of life for women and men with metastatic breast cancer, availability of support services, and the state of public awareness of metastatic breast cancer.

Posted 10/9/16

Share your thoughts on this XRAYS article by taking our brief survey.

References

World Health Organization Breast Cancer Awareness Month


Metastatic Breast Cancer Alliance “Changing the Landscape for People Living with Metastatic Breast Cancer,” October 2014

Questions to Ask Your Doctor

- I have metastatic breast cancer; should I have genetic testing?
- Who should I contact to have genetic testing?
- Should I have additional testing on my tumor to guide my treatment?
- What else can I do to maximize my health and wellbeing?
Study: Breast cancer screening should be tailored to a woman’s risk factors and breast density

SUMMARY

The United States Preventative Services Task Force (USPSTF) recommends a screening mammogram every other year for women ages 50-74 who are at average risk for breast cancer. But do all patients in this category benefit from this screening regimen? 10/18/16

STUDY AT A GLANCE

This study is about:
Using personal breast cancer risk and breast density to determine the frequency of screening mammograms for women over age 50.

Why is this study important?

This article is relevant for:

- Women who are at high risk for breast cancer due to family history, dense breasts, LCIS, or multiple biopsies

This article is also relevant for:

- Healthy people with average cancer risk
- Women over 45
The widespread use of screening and treatment has resulted in fewer breast cancer deaths for women in the United States. But along with the benefits, some harms come from detection and early intervention.

**Study findings:**

1. Using a computer model, researchers predict that screening mammograms every three years for women who are age 50 and older with average risk for breast cancer and low breast density produces similar or better benefits and harms compared to women who are at average risk and get mammograms every two years.

   - The model predicts that approximately 150 false-positive mammograms will occur to avoid one breast cancer death if women at average risk who have low breast density are screened every two years. It also predicts that with triennial screening, approximately 125 false-positive mammograms will occur to avoid one death due to breast cancer. This means that according to the model predictions, screening women at average risk every three years will lessen the number that receive false-positive mammograms to save one life.

2. Using a computer model, researchers predict that screening mammograms every year for women who are age 50 and older with higher risk for breast cancer and high breast density produces similar or better benefits and harms compared to women who are at average risk and get mammograms every two years.

   - This means that annual screening mammograms are more beneficial for women with high breast density and high risk for breast cancer, because they have a better balance of benefits (more breast cancer deaths avoided) and harms (false-positive mammograms, benign biopsies) than women at average risk who get mammograms every two years.

**What does this mean for me?**

This study uses computer models to suggest that breast cancer screening intervals can be tailored to each woman depending on her breast cancer risk and breast density. Researchers did not study actual patients who had screening every one, two or three years. Instead, they modeled and predicted what would happen if these women were to use these screening intervals. More work needs to be done to understand how we can tailor screening intervals for each patient. Currently, patients and their health care providers should work together to determine a patient’s optimal breast cancer screening interval based on her personal breast cancer risk factors.

Posted 10/18/16

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/risk-based-breast-screening).

**References**

https://www.facingourrisk.org/XRAY/risk-based-breast-screening


Disclosure

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WHO COVERED THIS STUDY?

**Reuters**
Also published in:
The same article was also covered by

- [Fox News](https://www.facingourrisk.org/XRAY/risk-based-breast-screening)
- [Yahoo News](https://www.facingourrisk.org/XRAY/risk-based-breast-screening)

*Women with dense breasts may need annual mammograms* ★★★★★ ★

**ABC News**

*Breast density matters for cancer screening, study finds* ★★★★★ ★

**Medical Xpress**

*Breast density and risk may be useful for guiding mammography screening frequency* ★★★★★ ★

**Cancer Therapy Advisor**

*Breast density and risk factors indicate breast cancer screening intervals* ★★★★★ ★

How we rated the media

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**IN-DEPTH** (click to expand)

View All

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**SEARCH XRAY STUDIES AND ARTICLES**

Keyword:  

Cancer Type:

Choose

Relevant for:

Choose Cancer Type First...

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**Categories:**

- [Alternative Treatments](https://www.facingourrisk.org/XRAY/risk-based-breast-screening)
- [Basic Science](https://www.facingourrisk.org/XRAY/risk-based-breast-screening)

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https://www.facingourrisk.org/XRAY/risk-based-breast-screening
Study: Breast cancer mortality among Hispanic women in the United States varies by country of origin

SUMMARY

"Hispanic" is a broad ethnic category that includes people from numerous countries. When discussing breast cancer statistics, Mexicans, Cubans, Puerto Ricans and people whose families originated in Central and South America are typically grouped into one Hispanic category. A new study looked at whether the country of origin affected breast cancer prevalence and mortality rates in Hispanic women in the U.S. (10/25/16)

Este artículo está disponible en español.
Why is this study important?

Public health researchers typically group people from all Hispanic subgroups into one category. But research on differences in mortality and morbidity (how often a disease occurs in an area) revealed many differences regarding health outcomes and behaviors among Cuban, Mexican, Puerto Rican, and Central and South American people. By combining all of the information on these subgroups into one Hispanic category, researchers are not getting an accurate picture of any subgroup.

Study findings:

1. This study found that the overall breast cancer mortality rate per 100,000 women in each group was:
   - all Hispanic women in the United States: about 18 deaths
   - women of Cuban descent: about 18 deaths
   - women of Mexican descent: about 19 deaths
   - women of Puerto Rican descent: about 19 deaths
   - women of Central or South American descent: about 10 deaths

What does this mean for me?

The results of this study suggest that breast cancer mortality rates for Hispanic women differ based on the country of origin. More work needs to be done to understand the biological reason why these differences may exist. Hispanic women should work with their health care providers to determine their breast cancer risk and discuss the appropriate time to start screening and ways to lower their breast cancer risk.

Posted 10/25/16

Share your thoughts on this XRAYS article by taking our brief survey.

References


Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

Latin Times
Breast Cancer: New study shows place of origin may impact A Latina's survival rate ★★★★★☆

Fox News Latino
A new study says place of origin may impact a Latina's breast cancer survival rate ★★★★★☆

The Hill
Breast cancer: A look at trends in the Latina American community ★★★★★☆

USA Today
Certain Hispanic women more likely to die of breast cancer than others ★★★★★☆

How we rated the media

IN-DEPTH (click to expand)

View All

SEARCH XRAY STUDIES AND ARTICLES

Keyword: 

Cancer Type:
Choose

Relevant for:
Choose Cancer Type First...

Categories: ⬜AND - ⬜OR

☐ - Alternative Treatments
☐ - Basic Science
☐ - Cancer Diagnosis
☐ - Cancer Risk
☐ - Cancer Treatment
☐ - Clinical Trials
☐ - Emotional Health

https://www.facingourrisk.org/XRAY/breast-cancer-in-hispanic-women
Study: Removing ovaries before age 50 may increase the risk of chronic conditions for some women

SUMMARY

Removal of ovaries and fallopian tubes prevents ovarian cancer, but it may come with other health risks. Experts recommend removal of ovaries and fallopian tubes in women at high risk for ovarian cancer due to inherited mutations in BRCA or other genes linked to ovarian cancer risk. For these high-risk women the benefit of ovarian cancer prevention outweighs the risk of long-term complications. Based on a recent study, some researchers feel that for women who are not at increased risk for cancer, the risk for some chronic conditions is too high to consider removal of both ovaries. (11/1/16)

This article is relevant for:

- Women under 50 years of age who have had or are considering removing their ovaries
- Previvors
- BRCA mutation carriers
Whether there is a connection between women who had their ovaries removed before age 50 and an increased risk of common chronic conditions, such as depression, asthma, coronary artery disease, and osteoporosis.

**Why is this study important?**

Researchers want to better understand the risks and benefits of ovary removal before age 50. Preventing ovarian cancer is a benefit of this procedure. However, ovaries produce hormones and removing ovaries at a young age can increase the risk for other diseases. Women need to understand the benefits and risks of ovary removal in order to make informed decision about the procedure. For women with an average chance for developing ovarian cancer, the risks that result from losing these sex hormones may not outweigh the benefit.

**Study findings:**

1. Women who had their ovaries removed before age 46 were at increased risk of depression, hyperlipidemia (high cholesterol and/or triglycerides in the blood), heart disease, coronary artery disease, arthritis, lung issues such as asthma and chronic obstructive pulmonary disease, and bone loss (osteoporosis).

2. Women who had their ovaries removed between ages 46 and 49 were at increased risk for depression, anxiety, hyperlipidemia, diabetes, arthritis, and cancer (all types).

3. Women who received estrogen therapy were able to reduce some of these increased risks.

**What does this mean for me?**

While the results of this study suggest that having ovaries removed before age 50 may increase a woman’s risk of some chronic conditions, it is important to note that the women in this study were not at increased risk for ovarian cancer. Generally, more work needs to be done to confirm and understand these findings. Women should work with their doctors to weigh their personal risks for ovarian cancer and determine whether or not they want to remove their ovaries, and if so, at what age. Women should also speak with their healthcare team to decide if they are candidates for estrogen replacement therapy.

Women diagnosed with breast cancer before age 50 meet national guidelines for genetic counseling and testing to see if they have an inherited mutation that increases breast and/or ovarian cancer risk. These guidelines recommend removing the ovaries and fallopian tubes for women who have a mutation in BRCA1 or BRCA2. Women with mutations in BRIP1, RAD51c, RAD51d, and the genes associated with Lynch syndrome should consider removal of their ovaries.

Posted 11/1/16
The National Comprehensive Cancer Network (NCCN) provides guidelines for management of gynecologic cancer risk in people with BRCA1 and BRCA2 mutations.

**Prevention**

- Risk-reducing removal of ovaries and fallopian tubes, (known as salpingo-oophorectomy) is recommended between ages 35-40 for BRCA1 and 40-45 for BRCA2 and upon completion of childbearing.
  - Research studies have shown that removing the ovaries can increase how long women with BRCA1 mutations live.
  - Women should talk with their doctors about the effects of early menopause and options for managing them.
- Women should talk with their doctors about the risks and benefits of keeping or removing their uterus (hysterectomy), including:
  - Women with a BRCA1 mutation have an increased risk for a rare form of aggressive uterine cancer; hysterectomy removes this risk.
  - For women considering hormone replacement after surgery, the presence or absence of a uterus can affect the choice of hormones used.
    - Estrogen-only hormone replacement is less likely to increase the risk for breast cancer. However, estrogen-only hormone replacement increases the risk for uterine cancer. Women who still have their uterus are typically given estrogen and progesterone hormone replacement.
    - Adding progesterone to estrogen hormone replacement can protect against uterine cancer. However, the combination of these hormones may increase the risk for breast cancer than estrogen alone.

Reference


Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

**Science Daily**
Ovarian removal to prevent ovarian cancer should not be an option for premenopausal women, research finds

**Ovarian Cancer News Today**
Preventative ovary removal in premenopausal women should be discontinued, researchers warn

**CNN**
Study: Removing both ovaries speeds aging in premenopausal women

How we rated the media

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SEARCH XRAY STUDIES AND ARTICLES

Keyword: 

Cancer Type: 

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Categories:

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure
Personal Story: CBS News brings attention to the issues facing young metastatic breast cancer patients

SUMMARY

Beth Caldwell is a former civil rights lawyer, a mother of two, and a wife who was diagnosed with stage 4 metastatic breast cancer when she 37. Mary Brophy Marcus covered Beth’s story in her piece, “The hardest part” of breast cancer under 40, for CBS News. (11/8/16)

This article is relevant for:
- Women diagnosed with metastatic breast cancer

This article is also relevant for:
- Breast cancer survivors
- ER/PR +
Younger women diagnosed with breast cancer face different issues than older women.

Since Beth was diagnosed at a young age, she has had some different concerns than older diagnosed women. Beth is often the youngest patient in her oncology clinic, as the average age of breast cancer diagnosis is typically in the 60s for women. “Younger women often feel isolated because they don’t know other women their age who have had breast cancer,” says Dr. Julie Gralow, the director of breast medical oncology at Seattle Cancer Care Alliance, in the piece.

The story highlights Beth’s difficulties relating with other young women who don’t have cancer: “The women at school, the ones you only know through your children, those conversations often remain very awkward. A few I’ve remained friends with. But it’s the ‘broken neck sad face’ – they tilt their head sideways and make that sad, pitying face.”

In some cases, younger women with breast cancer may also be dating -- How do you bring up a cancer diagnosis to a new partner? And a cancer diagnosis still brings many stresses to married couples. If the diagnosed patient does not have a caring partner, it can make problems that already exist worse and also cause new problems. The CBS news story takes notice that some partners may not be able to handle the fact that their partner may die.

Women who are diagnosed during childbearing years may have still wanted more children or have young children. Women who wish to have children may wonder how their treatment may influence their ability of becoming pregnant. Those with young children must balance motherhood with treatment and find ways to talk to their children about breast cancer. In the CBS News story, how it will affect her children is featured as one of the hardest parts of Beth’s diagnosis. Beth talks about conversations she has had with her children throughout the piece. She is honest with them, but says it is hard.

Metastatic breast cancer is different from early breast cancer

Women who are diagnosed with cancer at a younger age typically have more aggressive cancers. And while breast cancer is curable when it is caught early, once the cancer has spread beyond the breast and lymph nodes (1), there is currently no cure – only treatment. The special needs of women with metastatic breast cancer are also highlighted in the CBS News story. Beth tells us in her own words-- “For many, in the early stage (1), it’s like, ‘You’re in the sorority now,’ but that really didn’t fit with the life I was living and the fears I have to live with and that the median survival for it is still pretty short. I think I felt most alone at that point.”

After her diagnosis, Beth had to give up her position as a civil rights lawyer. “When I was first diagnosed, I knew I was stage 4 and I thought I’d go through heavy-duty treatment for a bit and it’d go back to normal, but that
was sort of a pipe dream. It’s not the way stage 4 works,” Beth says in the piece. Cancer treatment can take a toll of the body and many people find it difficult to work or are not able to work.

Other ways breast cancer before age 50 is different

Most women diagnosed before age 40 are not getting regular mammograms. Beth found a lump in her breast when she was 37, and was diagnosed after telling her doctor about it. The American Cancer Society (ACS) recommends that all women should “be familiar with how their breasts normally look and feel and report any changes to a health care professional right away.” While there is some controversy on testing women for breast cancer before age 50, many organizations including the National Comprehensive Cancer Network (NCCN), the American Medical Association (AMA), the American College of Radiology (ACR), and the American Congress of Obstetricians and Gynecologists (ACOG) recommend annual mammograms beginning at age 40, while the American Cancer Society (ACS) recommends beginning at 45.

One thing that this CBS News piece did not bring up is genetic testing. All women diagnosed with breast cancer before age 50 meet national recommendations for genetic testing. Breast cancer at age 37 alone qualifies a woman for testing but many may think they are only at risk if they have a family history of breast cancer. It is important to remember that there are reasons why a family history of breast cancer would not be easily identified, such as small family sizes or a family with mostly men (while men with mutations are more likely to get breast cancer than men of the average population, the chance is still not nearly as high as it is for women). Knowing if you have a mutation in BRCA1 or another gene that increases your chance of being diagnosed with cancer has further implications, such as your likelihood for other cancers and cancer in other family members, and the possibility of qualifying for clinical trials of drugs that target specific mutations, such as PARP inhibitors.

What can be done?

Beth talks about how attending a conference held by Living Beyond Breast Cancer (LBBC) helped ease her feelings of isolation. She was able to meet people who were experiencing the same things she was.

There are a number of advocacy organizations that hold conferences for women with breast cancer, now.

At the LBBC conference, Beth learned that the majority of research funding does not go to metastatic breast cancer research, and she began to advocate for increased funding. There are many opportunities for young breast cancer survivors and people with metastatic breast cancer to become more involved in advocacy. Training programs for patients include:

- FORCE’s FRAT Program (FORCE Research Advocate Training), which
trains people to become engaged in research advocacy on behalf of the hereditary breast and ovarian cancer community.

- YSC’s RISE (Respected Influencers Through Science and Education) Program trains people to become educated in all aspects of breast cancer.

- LBBC’s Young Advocate Program trains young women to use their personal experience with breast cancer to raise awareness and advocate for others.

**Conclusions**

In all, the CBS News story provided a window into the issues faced by young women with breast cancer and women with metastatic breast cancer and pointing out some of the resources available. FORCE XRAYS hopes more outlets will feature stories of women with different breast cancer experiences.

Posted 11/8/16

Share your thoughts on this XRAYS article by taking our brief survey.

**References**


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**Questions to Ask Your Doctor**

- I’m experiencing the following (e.g. pain, loss of appetite, anxiety, etc.), can a supportive care specialist help me? Does your practice have supportive services available?

- My family member or caregiver is having a difficult time coping with my diagnosis. Can a supportive care specialist help them?

- What supportive services would you recommend for me?

- Does your hospital have a support group for people with metastatic breast cancer?

- Are there any on-line support groups you would recommend for me?
Personal Story: Why one woman passed on genetic testing

SUMMARY

What are reasons to get or not get genetic testing? Cynthia Graber gives her thoughts on the matter in her Wired opinion piece, "Why I Won't Get the Genetic Test for Breast Cancer." (11/15/16)

This article is relevant for:
- People considering genetic testing and people who are Ashkenazi Jewish
- Healthy people with average cancer risk
- People with a genetic mutation linked to cancer risk
- Previvors
- Women under 45

What factors into your decision on whether or not to get genetic testing?

Cynthia Graber offers her thoughts on that question in her Wired opinion piece, “Why I Won’t Get the Genetic Test for Breast Cancer.”

Why she was thinking about genetic testing:
In her piece, she talks about her mom calling her one day urging her to get tested for the BRCA() mutations. Cynthia is an Ashkenazi Jewish() woman with some history of breast cancer on her dad’s side of the family (her dad’s great aunt and cousin both died of breast cancer). “She insisted. I immediately said no,” Cynthia writes. She recognizes that there is an increased likelihood of getting cancer for people with those gene mutations. Women in the general population have about a 12% lifetime chance for developing breast cancer. Women who carry a BRCA mutation have about a 45-65% lifetime chance for developing breast cancer. Their likelihood of developing ovarian cancer increases also—women generally have about a 1% chance of developing ovarian cancer compared to about 10-40% likelihood for women with a BRCA mutation.

Additionally, Cynthia’s Ashkenazi Jewish ancestry puts her at a higher chance for having inherited the BRCA mutation than the general population. An estimated 1 in 300-500 people in the United States has a BRCA mutation. In the Ashkenazi Jewish population, it is 1 in 40 people.

**Why she won’t get the genetic test for breast cancer:**

Cynthia knows that research shows surgery that removes breasts and ovaries in women at high risk of developing cancer greatly reduces their chance of developing cancer in the future. But then, she rightly says that, “every BRCA-positive woman has to weigh the strength of that survival data against the repercussions of surgery.” She talks about losing sensation in her breasts— “a crucial part of my sexual enjoyment.” She notes that after taking out her ovaries, she wouldn’t be able to have children. Also, it will put her into early menopause, which research has suggested may increase a woman’s chance of bone weakening and cardiovascular disease.

Surgery is not for her. But what about having twice-yearly breast cancer screening? This is also not for her because the chance of finding something on a scan increases greatly when someone is getting frequent mammograms and MRIs. She writes, “patients tend to pounce on those shadows. After years of tests and biopsies, some women give in and remove their breasts.”

She interviewed Barry Kramer, the director of the NCI’s division on cancer prevention, for her piece, who then talked about how the number of women undergoing mastectomies have increased even though there has not been much evidence pointing to a survival benefit. But the “patients are petrified,” he says. So “they take drastic, potentially harmful-and sometimes unnecessary-action.” Earlier in the article, she notes that there is evidence that surgery increases survival in women with BRCA mutations. This is likely a reference to well established survival benefit of risk-reducing removal of the ovaries and fallopian tubes().

Ultimately, because of her limited family history of breast cancer and lack of history of ovarian cancer, she chose not to get testing because of what it would mean to her. A positive test would not make her want to get any
surgeries. What a positive test would feel like to her though, is “hefting a sword, dangling it by a frayed thread above [her] head, and waiting for it to fall.” She says she is more afraid of living like that than she is of cancer.

It’s important to note that she has not had breast cancer and there is not a known BRCA mutation in her family. Under these circumstances many women make a different decision. However, family cancer history can change if more relatives are diagnosed with breast or ovarian cancer, or if a close family member discovers they carry a mutation in BRCA. In these cases, people who previously decided against genetic testing may change their mind. Discussing your family cancer history in light of any new cancer diagnosis is important for anyone concerned that the cancer in their family might be hereditary.

**Should you get genetic testing?**

Cynthia has very valid reasons to not get genetic testing based on her principles and what she wants from life.

However, it should be emphasized that these are her personal reasons and choices.

As she mentions in the article, she spoke with a woman, “who decided, after much agonizing, to take the BRCA test and then remove her breasts and ovaries. She didn’t regret it.” While Cynthia fears the results of a positive test looming over her life, other women want to know their risk so they can be proactive and either remove their breasts and ovaries, take risk-reducing medications, or get more frequent cancer screening.

**What are the signs of hereditary cancer?**

Typical signs that a mutation linked to hereditary breast and ovarian cancer may run in your family include:

- Breast cancer at age 50 or younger
- Ovarian, fallopian tube, or peritoneal cancer at any age
- Breast cancer in both breasts at any age
- Both breast and ovarian cancer
- Male breast cancer at any age
- *Triple-negative breast cancer* before age 60
- Ashkenazi Jewish heritage and breast cancer

More than one relative on the same side of the family with any of these cancers:

- Breast cancer
- Ovarian or fallopian tube cancer
- *Prostate* cancer
Pancreatic cancer

Melanoma

The cost of genetic testing has been declining over the past few years, and many insurance policies cover genetic counseling and testing for women with a family history of cancer.

Men carry BRCA mutations too

Lack of a strong family history of cancer or cancers at a young age does not mean a person does not carry a mutation. Certain aspects can mask a family history, such as a small family size and sex differences in some cancer mutations. BRCA mutations tend to affect women more profoundly than men simply because women have more breast tissue and men do not have ovaries—the two main cancers that are associated with BRCA mutations. Because of this, a mutation can easily go unnoticed in men. But it is important to remember that men with BRCA mutations have an increased risk of male breast cancer, prostate cancer, pancreatic cancer, and melanoma. The presence of these cancers in men in the family can also be a sign of hereditary cancer. Men who carry mutations in BRCA have a 50% chance of passing it down to their sons or daughters, so it is critical to pay attention to cancer history on both sides of the family.

Importance of genetic counseling

Cynthia does not mention whether or not she had genetic counseling before she made her decision. Experts recommend people who are concerned that the cancer in their family might be hereditary consult with a genetics expert. A genetic counselor will look at a person’s personal and family history of cancer, and give them information on the current recommendations for risk management. Talking to a genetic counselor or other genetics expert before testing can help a person decide if genetic testing is right for them. In the case of a person with a family history of cancer but no known mutation, a genetic counselor can help identify the best person in the family to test first.

Getting genetic testing is a personal decision. Cynthia’s piece should not be used as a reason to not pursue testing. If a person is still unsure about genetic testing after thinking about it and discussing it with a genetics expert, then it makes sense to not get genetic testing at that time. The important thing is that each person makes the decision that they are comfortable with.

Posted 11/15/16

Share your thoughts on this XRAYS article by taking our brief survey.

References

Graber, C. "Why I Won’t Get the Genetic Test for Breast Cancer." Wired.
Published online on Sept. 27, 2016.
NCCN guidelines recommend genetic counseling and testing for people without cancer who have the following family history:

- A relative who has tested positive for an inherited mutation in a gene that increases cancer risk.
- One or more first- or second-degree relatives with breast cancer and any of the following:
  - diagnosed at age 45 or younger
  - triple-negative breast cancer
  - two separate breast cancers, with the first diagnosis at age 50 or younger
  - male breast cancer
- One or more first- or second-degree relatives with:
  - colorectal cancer before age 50
  - endometrial cancer before age 50
  - ovarian, fallopian tube, primary peritoneal cancer
  - rare or childhood cancers
- One or more first-degree relatives with:
  - metastatic (or high-grade) prostate cancer
  - pancreatic cancer
- Two or more relatives on the same side of the family diagnosed with any combination of the following at any age:
  - breast cancer
  - pancreatic cancer
  - prostate cancer
  - melanoma
  - sarcoma
  - adrenal cancer
  - brain tumors
  - leukemia
  - endometrial cancer

Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
Study: Cancer treatment costs can vary widely

SUMMARY

Healthcare providers cannot give their breast cancer patients information on chemotherapy treatment costs because not enough is known about the exact costs. New research finds that costs vary not only between different cancer treatments, but also between similar treatments, such as all treatments that target HER2+ breast cancer. (11/22/16)

This article is relevant for:

- People diagnosed with breast cancer

This article is also relevant for:

- Breast cancer survivors
- ER/PR +
- Her2+ breast cancer
- Men with breast cancer
- Metastatic cancer

https://www.facingourrisk.org/XRAY/costs-of-cancer-treatment
Cost is an unfortunate but important factor for patients when deciding on a treatment regime. Even patients who have insurance may have high out-of-pocket costs. Healthcare providers want to give their patients the best treatments possible and patients want these treatments, but what if that is something patients can’t afford? Previous research established a link between high costs of cancer care and lower adherence to medications, and increased risk of bankruptcy as well as psychological and material difficulties. Additionally, while healthcare providers know that communicating treatment costs is important for patients, it does not often occur because cost information is simply not available.

**Study findings:**

1. The median insurance payment for patients who have private insurance and received one of the trastuzumab (Herceptin)-based treatments (the targeted therapy for HER2+ breast cancer) was $160,590. The median out-of-pocket payment was $3,381. This means that about half of the patients paid more than $3,381 and about half paid less.

   - 25% of patients paid more than $5,604 out-of-pocket and 10% paid more than $8,384 out-of-pocket.

2. The median insurance payments for patients who have private insurance and received one of the non-trastuzumab treatment (for patients with HER2- breast cancer) was $82,260. The median out-of-pocket payment was $2,724. This means that half of patients paid more than $2,724 and half paid less.

   - 25% of patients paid more than $4,712 out-of-pocket and 10% paid more than $7,041 out-of-pocket.

**What does this mean for me?**

This study suggests that breast cancer treatment costs can be very different depending on the type of treatment and the patient’s insurance coverage. The authors of this study wrote, “Because of the rising costs of care and increased cost-sharing for patients, the expense of treatment is becoming more relevant to patients and their families, and providers need more accessible information to be able to answer patients’ questions about the financial impact of their treatment choices.” More work needs to be done so healthcare providers can have this information for their patients.

Posted 11/22/16

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/costs-of-cancer-treatment).

**References**

Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

Questions to Ask Your Doctor

- How much will my treatment cost?
- Will insurance providers cover this treatment cost?
- What are the projected copays or deductibles associated with my cancer treatment with my insurance coverage?
- Are there any options or financial arrangements that will allow me to pay my treatment costs over time?
- Are there open clinical trials that are appropriate for me?
- If alternative treatments are available, what are the benefits, risks and costs of each?
The following resources focus on financial resources for people with, or at high risk for cancer.

- **FORCE resources**
  - Information: [Insurance and paying for care](#)
  - Information: [Health insurance appeals: Medicare and Medicaid](#)
  - Video: [Health Insurance and Your Legal Rights](#)
  - XRAY category: [Financial issues](#)
- **Triage Cancer**
- **Patient Advocate Foundation**
- **Cancer and Careers**
- **Lazarex Foundation** offers assistance to cover costs for travel and related expenses for clinical trials.

**Updated: 12/22/2021**

**WHO COVERED THIS STUDY?**

**Reuters**

Also published in:

The same article was also covered by Fox New and Yahoo.

**Breast cancer chemo costs vary despite similar effectiveness**

**Medical News Today**

**Breast cancer: Similarly effective treatments vary in cost**

**NBC News**

**Breast cancer treatment costs vary wildly, study finds**

How we rated the media

**IN DEPTH REVIEW OF RESEARCH**

Study background:
Cost of treatment is an important subject that many patients want their healthcare providers to address. This is especially important for patients who have the choice between similar treatment options. HER2+ and HER2- breast cancer patients have quite a few options to choose from—the National Comprehensive Cancer Network guidelines identify 12 acceptable chemotherapy regimens for HER2- breast cancer patients and 9 acceptable chemotherapy regimens for HER2+ breast cancer patients. Unfortunately, not a lot of cost information is available for healthcare providers to share with their patients to help them with these decisions.

Sharon Giordano and colleagues from The University of Texas MD Anderson Cancer Center published work in 2016 in the journal Cancer to get a better idea of breast cancer treatment costs for breast cancer patients.

Researchers of this study wanted to know:

What are the costs for U.S. breast cancer treatment from both the insurance companies’ and patients’ perspective?

Population(s) looked at in the study:

The 14,643 women in this study were 18-years-old or older and had breast cancer diagnosed between 2008 and 2012. About 24% received therapy that included the trastuzumab (Herceptin), a targeted therapy for HER2+ cancer, while 77% received non-trastuzumab regimens including taxanes such as docetaxel, platinum-based drugs such as carboplatin, and anthracyclines. Women in the study also had surgery, and, where appropriate, hormone therapy. All women in the study had private insurance and received treatment within 3 months of diagnosis. Costs were evaluated for up to 18 months after diagnosis.

Study findings:

1. The median insurance payments for patients who have private insurance and received one of the trastuzumab-based treatment (the chemotherapy for HER2+ breast cancer) was $160,590. The median out-of-pocket payment was $3,381.
   - 25% of patients paid more than $5,604 out-of-pocket and 10% paid more than $8,384 out-of-pocket. This means that about half of the patients paid more than $3,381 and about half paid less.

2. The median insurance payments for patients who have private insurance and received one of the nontrastuzumab treatment (for patients with HER2- breast cancer) was $82,260. The median out-of-pocket payment was $2,724. This means that about half of the patients paid more than $2,724 and about half paid less.
   - 25% of patients paid more than $4,712 out-of-pocket and 10% paid more than $7,041 out-of-pocket.

3. Costs varied within similar therapy regimens. For example, for patients who received a trastuzumab-based treatment, the median insurance payment costs differed by about $20,000.

Limitations:

This study does not include information on patients without insurance—these patients face considerably higher out-of-pocket costs.

Because this study used an 18-month time frame, the researchers could not estimate total costs of breast cancer care. For example, patients who underwent breast reconstruction beyond the 18-month window or may have received hormone therapy for 5-10 years. And because the source data used for this study were not linked to any cancer registry data, researchers were unable to look at the patients’ cancer stage, race/ethnicity or tumor characteristics.
Finally, the researchers were unable to look at newer drugs that have been released since the data was collected.

**Conclusions:**

This study suggests that breast cancer chemotherapy costs vary widely. More work needs to be done so healthcare providers can provide patients with accurate cost information. Until this happens, patients should have frank discussions with their healthcare providers about cost and how it will affect them.

Posted 11/22/16

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- Health Literacy
- Hereditary Cancer
- Intimacy & Body Image
- LGBTQIA+
- Male Breast Cancer
- Menopause
- Metastatic Cancer

https://www.facingourrisk.org/XRAY/costs-of-cancer-treatment
Personal Story: Men get breast cancer too

SUMMARY


Questions for your doctor

Risk for breast cancer in men

Genetic testing for men with breast cancer

Resources

Signs of breast cancer in men

In her article, Cathy Free addresses the misconception that men don’t get breast cancer by telling the stories of two male breast cancer survivors, Michael Singer and Bret Miller.

“Men have breasts too”
Michael Singer discovered he had breast cancer after he mentioned “on a whim” to his health care provider that he had a small lump under his left nipple. Singer had been ignoring this lump for months. The biopsy the health care provider ordered came back positive for stage 2 breast cancer.

Michael was surprised, because like many people, he didn’t think men got breast cancer. “I was embarrassed to talk about my diagnosis, except for telling my wife, Patty…I told everyone else that I had chest cancer because I just couldn’t go there with breast cancer. I felt like a freak. I felt extremely isolated.”

He was inspired to become an advocate for male breast cancer patients after watching a show that featured Bret Miller, the founder of the nonprofit Male Breast Cancer Coalition. Miller was diagnosed with breast cancer when he was 24 and had a mastectomy. He found a lump when he was 17, and experienced yellow-orange discharge from his nipples. “I want to tell men not to wait until it’s too late. Early detection saves lives, so go see a doctor if you find a lump, a discoloration or a discharge like I had.”

What does this mean for men and their breast cancer risk?

In the People piece, Free writes, “Although he’d lost his sister, Jo-ann Weiss, to breast cancer just two years before, it never occurred to Singer that breast cancer was an “equal opportunity” killer, with 2,600 men diagnosed yearly and about 440 of those dying…”

According to the American Cancer Society, the lifetime risk of breast cancer for men at general risk is about 1 in 1,000. Among 1,000 women at general risk, about 124 will develop breast cancer. This means that women are 100 times more likely to get breast cancer compared to men, so it is inaccurate to say that breast cancer is an “equal opportunity” killer. However, this does not mean that men do not get breast cancer—some men do, and it is important when men like Michael Singer and Bret Miller bring awareness to other men so that they know to act on symptoms such as lumps in their breasts and discharge from their nipples.

Mutations in BRCA and other genes increase cancer risk in men

The story mentions that Michael’s sister had breast cancer, but does not mention whether anyone in his family had genetic testing. Bret had breast cancer at a young age. A sibling with breast cancer and onset at an early age are both signs that there may be an inherited mutation in BRCA or another gene that increases cancer risk in the family. Not all men with breast cancer have inherited mutations, but those who do are at higher risk.

About 60 of 1,000 men with BRCA mutations will develop breast cancer, while about 10 in 1,000 men with BRCA mutations develop breast cancer. While this is much higher than men in the general population, it is important to note that these numbers are lower than the breast cancer risk of women in the general population. The National Comprehensive Cancer Network.
(NCCN) Guidelines for men with BRCA mutations include both breast self-exam education and annual clinical breast exam beginning at age 35. Men with inherited mutations in BRCA also have increased risk of aggressive prostate (I) cancer at younger ages, and should consider regular prostate cancer screening.

All men with breast cancer meet national guidelines for genetic counseling and testing

NCCN guidelines recommend genetic counseling and testing for all men with breast cancer, regardless of their age at diagnosis. If you have an inherited mutation in BRCA1 or BRCA2 and develop breast cancer, you may qualify for certain clinical trials, such as those involving PARP inhibitors. Men with mutations in genes that increase cancer risk also have a 50% chance of passing the mutation down to their sons and daughters. Genetic counselors can help men with breast cancer decide if genetic testing is appropriate.

Signs of breast cancer in men

The American Cancer Society notes the following signs of breast cancer in men:

- Breast lump
- Skin dimpling or puckering
- Nipple turned inward
- Redness on breast or nipple
- Scaling on breast or nipple
- Discharge from the nipple

Ultimately, men should be aware of changes in their body. "If I had known that the yellow-orange discharge I was seeing was a major sign of breast cancer, I would have been proactive and gone in much earlier," Bret Miller shared in the People piece. Even though the risk of men developing breast cancer is low, it is not impossible, so men should report any of these changes in their breasts to a healthcare provider.

Posted 11/29/16

Share your thoughts on this XRAYS article by taking our brief survey.

References:

American Cancer Society Key Statistic About Breast Cancer in Men

American Cancer Society Signs and Symptoms of Breast Cancer in Men

Article: Headlines claim drug combination destroys tumor in 11 days—is this too good to be true?

SUMMARY

A recent IFLScience headline proclaimed “Remarkable Breast Cancer Trial Destroys Tumors in Just 11 Days.” This sounds amazing but it leaves out key facts. First, the finding applies only to HER2-positive breast cancer, not all breast cancers. More importantly, the results are from a conference presentation and have not yet appeared in a peer-reviewed scientific journal. What does that mean for breast cancer patients? (12/6/16)

Read the article that we reviewed

IFLScience published a piece with the exciting headline “Remarkable Breast Cancer Trial Destroys Tumors in Just 11 Days,” based on preliminary trial results presented by Dr. Nigel Bundred, a professor of surgical oncology at The University of Manchester, at the 10th European Breast Cancer Conference.

About the research

The trial results show early promise. The trial looked at 127 women who had newly diagnosed HER2-positive breast cancer and were randomized to receive either a control drug, trastuzumab (know as Herceptin®) only, or...
trastuzumab in addition to lapatinib (Tykerb®) for eleven days before surgery. The researchers studied breast biopsy tissue taken before the women received their drugs and compared it to the tissue removed at the time of surgery (after they received their drug) to see if the drugs affected cellular growth of the tumor, whether the women had a pathological complete response (no active cancer cells were found) or minimal residual disease (the tumor was smaller than 5mm in diameter).

Among women who were on the combination of Herceptin and Tykerb:

- all of them showed a decrease in cell growth
- 11% had a pathological complete response
- 17% had minimal residual disease

Among women who received only Herceptin:

- None had a pathological complete response
- 3% had minimal residual disease

The researchers stated that the complete results of their study, including details about cell growth in women who received Herceptin only will be available later.

**What does this mean for me?**

These are promising results for women with HER2-positive breast cancer because as Dr. Judith Bliss, one of the lead researchers of the study said in a press release last March, “These results show that we can get an early indication of pathological response within 11 days, in the absence of chemotherapy in these patients on combination treatment. Most previous trials have only looked at the pathological response after several months of treatment.”

However, these results **do not change clinical practice**. Presenting results at a conference is often the first step researchers take to share their findings with other researchers. **This is a very early step.** Researchers who are familiar with the subject area but not directly involved in the work have not yet formally reviewed the findings presented at these conferences. This important process, known as peer review, is a crucial step of the scientific process and every research finding is subjected to this when it is submitted to a scientific publication. Many times, studies presented at conferences are still ongoing, meaning the researchers most likely have more work and experiments to perform.

Despite the headline claiming that the treatment “destroys tumors,” these are preliminary results that do not say anything about whether women will have better long-term survival. Without results that indicate better long-term survival or another later endpoint, healthcare providers cannot skip giving chemotherapy to women just because they received Herceptin and Tykerb. Until the researchers publish their findings with the complete data and long-
term survival information from a clinical trial, these findings are far from definitive and clinically actionable. **Even if these results pan out, this treatment is only applicable to people with newly diagnosed HER2-positive breast cancer, which comprise about 10-15% of all breast cancers.**

More research will be done on the Herceptin and Tykerb drug combination to help women with HER2-positive breast cancer. While the IFLScience headline and other media articles covering this conference presentation sounded exciting (Tumors destroyed in 11 days!), we need to remember to read beyond the headlines to make sure what is said accurately describes what the researchers found.

Posted 12/6/16

Share your thoughts on this XRAYs article by taking our brief survey

**References:**

Lapatinib and trastuzumab shrinks HER2+ breast cancer in 11 days after diagnosis

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**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYs articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

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**Questions to Ask Your Doctor**

- Do I qualify for a clinical trials?
- What side effects should I expect from my treatment?
- Would I benefit from Tykerb?
Article: After mastectomy: reconstruct or not?

SUMMARY

Today, more women know they can have breast reconstruction after removing their breasts for cancer treatment or risk reduction. But what about choosing not to undergo reconstruction? Roni Caryn Rabin writes about the experiences of women who decide against reconstruction in her New York Times piece “‘Going Flat’ After Breast Cancer.” (12/14/16)

This article is relevant for:
- Woman who are facing mastectomy
- Breast cancer survivors
- ER/PR +
- Her2+ breast cancer
- People with a genetic mutation linked to cancer risk
- Preivors

Read the article that we reviewed

Contents

Positive side of reconstruction

Questions for your doctor

Negative side of reconstruction

Resources

Women have options

In Roni Caryn Rabin’s New York Times piece, “‘Going Flat’ After Breast Cancer,” she shares the experiences of women who chose not to have new breasts recreated after mastectomy.

Reconstructed breasts—the good

Speaking about breast reconstruction, Dr. David Song, Chief of Plastic Surgery at the University of Chicago, was quoted as saying, “...the aesthetic result can be better than the native breast...Patients can come out the other
end looking more youthful, with a better aesthetic in [the] breast than before.” Breast reconstruction, particularly bilateral reconstruction, provides an opportunity to improve upon cosmetic imperfections, and some women view it as a chance to go a bit bigger or a bit smaller.

More women than ever before know about their reconstruction options with breast implants or their own native tissue, even though many others are still uninformed about their choices—a good reason for women to research and understand the benefits and limitations of various alternatives to determine which, if any, is best for them. Many plastic surgeons and oncologists actively promote reconstruction to women who face mastectomy (although some still do not mention the option) often by citing studies that show women who undergo reconstruction have improved quality of life.

Thanks to women’s health advocates who fought for the Women’s Health and Cancer Rights Act of 1998, health care plans that cover the cost of mastectomy are now also required to pay for breast reconstruction and prostheses after mastectomy. The law also requires insurers to inform their patients of this optional but important benefit.

**Reconstructed breasts—the not so good**

“Some women say that doctors focus too much on physical appearance, and not enough on the toll prolonged reconstructive procedures take on their bodies,” Rabin writes. As with any surgery, reconstruction has risks, and complications sometimes occur.

Rabin quotes Dr. Clara Lee, an associate professor of plastic surgery at Ohio State University, who notes that the risk of a major complication is higher for reconstruction than for the average elective surgery, which she calls the “dirty little secret of breast reconstruction.” While some reconstructive procedures are relatively straightforward, others are complex and lengthy, adding to the increased risk of complications and the potential need for a return to the operating room.

Rabin’s article focuses on women who were dissatisfied with their reconstruction with breast implants. Marianne Cuozzo, for example, began reconstruction with breast implants, but after dealing with four infections in five months, she decided to have the implant removed. Sara Bartosiewicz-Hamilton tried having her breasts recreated with two different implants before she also ultimately chose to remove them because of a constant burning sensation.

Even when reconstructed breasts look the same or better than a woman’s natural breasts, the article notes that they are “often numb and can no longer play a role in sexual arousal.” The article mentions that one reason that reconstructed breasts may not look the same is because natural nipples are typically removed during mastectomy. It can then be recreated, but it will not have sensation or react to touch, and usually flattens over time. For this reason, many women choose to have nipples tattooed onto their new breasts.
breasts—lifelike 3-D nipple tattoos give the “illusion of protrusion.” Other women are satisfied to forego nipple reconstruction and/or tattoos. However, most women, except those with a malignancy in the nipple or the surrounding skin, can have a nipple-sparing mastectomy, which removes breast tissue but preserves their own breast skin and natural nipple.

Rebecca Pine, a patient profiled in the article, originally had reconstruction with a breast implant after a unilateral mastectomy to remove one breast. When she had a risk-reducing mastectomy on her other breast, she decided to have her implant removed, because her reconstructed breast was not receptive to feeling or touch and didn’t “look or feel, in most cases, like our breasts.” (Partial loss of sensation is an unfortunate side effect of mastectomy that isn’t typically restored with reconstruction.)

**Women have options**

“For years, medical professionals have embraced the idea that breast restoration is an integral part of cancer treatment,” Rabin writes. However, some advocates say patients should also be aware no reconstruction is also an option, and patients should not feel pressured into one choice or the other.

Some studies show that breast reconstruction improves quality of life while others suggest that quality of life is similar between women who have reconstruction and women who have not. While many studies have concluded that reconstruction improves self image and quality of life, an analysis of 28 previous studies found that women who did not have reconstruction did just as well regarding body image, quality of life, and sexual outcomes as women who had reconstruction.

While it is important to understand that not all women are satisfied with their reconstruction, this analysis has several limitations. Most studies reviewed were from a single institution between 1998 and 2009, and included only reconstruction with implants, TRAM, TRAM(1) flaps or latissimus dorsi flaps (which involve the loss of muscle to rebuild the breast)—the three oldest types of reconstruction. It did not include women whose reconstruction involved improved or more advanced options, such as newer generation implants, or muscle-sparing DIEP(1) flaps and TUG flaps. Nor did the review differentiate between saline or silicone devices, or include the use of highly cohesive gel breast implants (introduced in 2012), which typically have a very high patient satisfaction rate and now account for most reconstructions with breast implants. The analysis also excluded previvors who had reconstruction after risk-reducing mastectomy (a population that tends to have high satisfaction rates with reconstruction).

The author notes that for many women who do not have reconstruction, it can be hard to come to terms with a flat chest after breast cancer or risk-reducing mastectomy. With a flat chest, it may be difficult to find clothes that
fit properly, and though many types of prostheses can be worn in bras, camisoles and swimsuits or adhered to the chest, some women stop using these artificial forms because they can be heavy and uncomfortable.

It’s important to remember that this article specifically addresses women who were dissatisfied with their reconstruction and those who decided to go flat. It does not include women who were somewhat or very satisfied with their reconstruction, and who prefer to have reconstructed breasts, even if they do not restore sensation. Going flat after mastectomy is a personal choice that is right for some women, but not for others, and the decisions involved should not be taken lightly. As with many medical decisions, not all patients are alike, and each should be given the information about all viable options so they can make the choice that is best for them.

Patients making decisions about mastectomy and reconstruction are encouraged to speak to other women who have experienced the same choice through support groups and social media. Many options are available, and experts often advise consulting with multiple surgeons to better understand their choices and identify the skills of individual surgeons (not all surgeons perform all procedures). Ultimately, the most important thing is that the patients feel comfortable with the choice that they have made; that is more likely if they understand their options and make informed decisions.

Posted 12/14/16

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References:


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Personal Story: Male transgender breast cancer patient shares his experience in NYT piece

SUMMARY

Denise Grady’s New York Times piece presents the struggles faced by Eli Oberman, a male transgender patient who was diagnosed with breast cancer, including the difficulty of being the only male patient in gynecologist waiting rooms that are full of women. (12/21/16)

This article is relevant for:

- Transgender men with, or at high risk for breast cancer

This article is also relevant for:

- Men with breast cancer

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In "Living as a Man, Fighting Breast Cancer: How Trans People Face Care Gaps" (published October 16, 2016 in the New York Times), Denise Grady tells the story of Eli Oberman, a transgender man who was diagnosed with breast cancer at age 27.

Oberman’s story

Oberman began to take male hormones at age 19 to change his gender from female to male, but he had not yet had surgery. He initially wanted “top surgery,” which is breast removal that leaves some breast tissue to give the...
chest a “male-looking contour,” but he did not have this surgery due to its cost.

In 2010, he discovered a lump in his breast, and after 6-8 months, a scan and biopsy showed an aggressive cancer. His doctor recommended double mastectomy and chemotherapy.

**Struggles faced by transgender male breast cancer patients**

“The cancer was a stark reminder that [Oberman] was still vulnerable to illnesses from his original anatomy—and that the medical world has blind spots in its understanding of how to take care of trans men and women,” Grady writes.

Oberman discusses some of the negative experiences he and his transgender friends have had, including an incident when Oberman had to take off his shirt during a medical appointment for his breast cancer. As this was before his mastectomy, the male technician attending to Oberman saw his breasts and said, “Why would you do this to yourself? It’s disgusting.” Oberman had previously gone to a clinic that specialized in LGBT patients; he was afraid to plunge into the world of mainstream medicine (although he comments that doctors typically treated him with respect).

But experts say that transgender patient treatment is improving. The article notes that hospitals and professional schools have begun to train their employees and students to better care for transgender patients, but notes that there are still struggles. However, this training does not fix the fact that men with breast cancer may be “the lone male patient in waiting rooms full of women...” Experts also observe that transgender individuals are more likely to avoid screenings and medical care for parts of their bodies from their assigned sex.

This fear of acceptance was why Oberman never joined a breast cancer support group. And his hesitancy to continue his care with mainstream medicine continued after his breast cancer. He was afraid of being treated badly in a gynecologist’s office, recalling his friends’ experiences with receptionists who assumed they shouldn’t be there because of their deep voices. He waited five years after his breast cancer surgery before deciding to have his first Pap smear (for cervical cancer screening) at age 32; guidelines from the Centers for Disease Control and Prevention (CDC) recommend women begin having Pap smears at 21.

Oberman and his friends are not alone. Dr. Asa Radix, his physician and the senior director of research and education at the Callen-Lorde Community Health Center in New York, which provides health care for LGBT patients, said that trans men usually avoid gynecologists. “Imagine, if you’re a masculine-looking trans man, and you’re going to the gynecologist...You go to the front desk, and you have to out yourself. Everyone can hear what’s
going on. You just want to run out the door,” he said in the article. Additionally, some patients “may not want to think they have the anatomy they have,” he said.

Oberman also describes the effects of stopping his testosterone treatments (recommended by health care providers due to the possibility of the hormone interfering with healing after his mastectomy), as extremely hard for him emotionally: “I went insane. I wasn’t rational. I was lying on the floor, crying.”

This points to a larger problem: not a lot of data is available for guiding transgender patients regarding their hormones. While no evidence shows that the hormones transgender patients take increase the risk of cancer, there simply hasn’t been much study of it.

**Issues facing transgender people facing breast cancer risk**

Male transgender breast cancer patients have a unique and difficult struggle. Men in the general population typically don’t think about breast cancer risk, though they do have a small risk (~1/1000 men not affected by hereditary cancer, 1% get breast cancer, while 2-8% of men with BRCA mutations get breast cancer). However, for male transgender people who still have their breasts, this risk is likely closer to the risk (about 12% lifetime) of the average woman in the U.S. For male transgender people with mutations in BRCA or other genes that increase cancer risk, the lifetime risk is even higher.

Oberman mentioned that his mother and her mother both had breast cancer; while both diagnoses occurred after menopause, this information paired with his young age at his own diagnosis should have prompted genetic testing. Male transgender patients who have a family history of breast cancer or a mutation in a cancer risk-increasing gene, such as BRCA, are at even higher risk. Currently research on the effects of feminizing or masculinizing hormone treatment on cancer risk is limited, particularly for people affected by hereditary cancer. This can make decision-making even more challenging for transgender people with mutations in BRCA or other genes that increase cancer risk. FORCE has received questions that highlight this and other gaps in research and services, such as:

- What is the effect of feminizing hormones on breast cancer risk?
- Are people with BRCA mutations who take feminizing or masculinizing hormones at greater risk for cancer?
- Is enough breast tissue removed during masculinizing chest surgery to reduce breast cancer risk in BRCA mutation carriers?
- Do plastic surgeons have experience in performing male chest reconstruction after risk-reducing bilateral mastectomy? When is it indicated?

Posted 12/21/16
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Current recommendation for cancer screening in transgender people

In June 2016, the University of California Center for Excellence in Transgender Health published the second edition of Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People, which include the following guidelines for cancer screening and treatment:

- For transgender women, breast cancer screening beginning 5-10 years after use of feminizing hormones.

- For transgender men who have not had mastectomy or who had breast reduction rather than mastectomy, routine breast cancer screening based on personal and/or family history.

- Genetic counseling and/or testing if there is a known mutation in BRCA or other gene that increases breast cancer risk, or if the patient has a personal or family history of cancer that meets national guidelines for genetic counseling and testing.

- Screening for other cancers (e.g. cervical, endometrial, prostate, etc.) should be based on an individual’s personal and/or family history of cancer.

Both the New York Times article and the guidelines emphasize the need for health care providers to assure that the medical system is treating transgender patients with appropriate care.
Can some breast cancer patients skip chemotherapy safely?

Study: Can tumor tests identify more breast cancer patients who can safely skip chemotherapy?

**SUMMARY**

Two studies presented at the December 2020 San Antonio Breast Cancer Symposium looked at how tumor testing can identify patients who may benefit the most and the least from chemotherapy. (3/4/21)

*Este artículo está disponible en español.*

**CONTENTS**

- At a glance
- Study findings
- What does this mean for me?
- In-depth

**UPDATE AT A GLANCE**

**What are these studies about?**

These studies are about whether tumor tests can identify which breast cancer patients with cancer that has spread to their lymph nodes can safely skip chemotherapy and which patients are most likely to benefit from it.
Can some breast cancer patients skip chemotherapy safely?

Why are these studies important?
Chemotherapy has long been a part of breast cancer treatment. For many patients, it can have serious and/or long-lasting side effects. These studies looked at how some tumor tests may better identify breast cancer patients who can safely skip chemotherapy (without an increased chance of cancer coming back or recurring) and patients who can benefit from chemotherapy.

Oncotype Dx
Oncotype DX is a type of tumor test. It looks at which genes are active in cancer cells compared to healthy cells. The test assigns scores ranging from 0 to 100. A score of 25 or below suggests that there is a low risk of breast cancer coming back.

Oncotype DX risk scores are used to identify women with hormone-positive, Her2-negative, node-negative breast cancer who would benefit from chemotherapy. The TAILORx study showed that women with this type of early-stage breast cancer and an Oncotype DX recurrence score of 25 or lower did as well on hormone therapy alone as those who were given hormone therapy plus chemotherapy.

The results of TAILORx left an important question unanswered: What is the best way to treat women with early-stage breast cancer that has spread to the lymph nodes? Two recent studies, RxPONDER and ADAPT studied this question in different ways.

Can even more women safely skip chemotherapy?
The RxPONDER study findings
The RxPONDER study looked at the benefit of chemotherapy in women with early-stage breast cancer that had spread to one to three lymph nodes. About 5,000 patients were randomly assigned to receive hormone therapy alone or hormone therapy plus several months of chemotherapy. Each of these participants had all of the following:

- hormone-positive, Her2-negative breast cancer.
- 1-3 positive lymph nodes.
- an Oncotype Dx score of 25 or less.

Early (five year) results of the RxPONDER study presented at the 2020 San Antonio Breast Cancer Symposium showed that:

- no association was found between recurrence score and chemotherapy benefit. In other words, patients with higher recurrence
scores (e.g., up to 25) did not have greater benefit from chemotherapy than those with lower scores (e.g., 4, 5, 6).

- Among premenopausal women, those who received chemotherapy were more likely to be disease-free 5 years later than premenopausal women who received hormone therapy only.

- Among postmenopausal women, there was no difference in disease-free survival whether or not they had chemotherapy.

Based on these findings, many postmenopausal women may be able to safely skip chemotherapy. However, it is important to note that this study showed that there is benefit from combination chemotherapy and hormone therapy for premenopausal women.

Questions remain

Researchers will continue to follow patients for a total of 15 years. This will allow them to collect more data and get a better understanding of how these patients fare over time.

While the results of RxPONDER confirm earlier research that showed chemotherapy benefits premenopausal women, why that is so is unknown. One possible explanation is that chemotherapy can induce menopause, which in turn can starve Hormone-positive breast cancer cells of the estrogen they need to grow.

Additional research is needed to see if premenopausal women who are given menopause-inducing medications plus hormone therapy would respond more like the postmenopausal women in this study who did not benefit from chemotherapy.

The ADAPT study findings

Like the RxPONDER trial, researchers of the ADAPT trial wanted to know whether women with early-stage breast cancer that has spread to the lymph nodes would benefit from chemotherapy.

The ADAPT study looked at whether combining two tests, Oncotype Dx and a tumor marker called Ki-67 could help identify women who are most likely to benefit from chemotherapy and those who may safely skip chemotherapy.

Participants in the ADAPT study had hormone receptor-positive, Her2-negative breast cancer with zero or up to three positive lymph nodes. Unlike the RxPONDER study, all patients in this study received three weeks of hormone therapy after their initial biopsy and before surgery to remove their tumor.

Biopsy tissue was used to get an Oncotype Dx score and a first Ki-67 score. Tumor tissue removed at the time of surgery was used to get a second Ki-67 score.

https://www.facingourrisk.org/XRAY/skipping-chemotherapy
Researchers used Oncotype DX scores and changes in Ki-67 scores (at biopsy and after surgery) to decide who should receive chemotherapy with hormone therapy and who could receive hormone therapy alone after surgery.

People with Oncotype Dx scores of 12 or higher and Ki-67 scores of 10 percent or higher after three weeks of hormone therapy were given chemotherapy along with hormone therapy after surgery. The results of this group were presented in another presentation and are not included here.

The ADAPT study presents the results for the remaining 2,290 participants who were separated into two groups:

- Those with an Oncotype Dx score of 0 to 11 and 0 to 3 positive lymph nodes.
- Those with an Oncotype Dx score of 12 to 25, 0 to 3 positive lymph nodes and a second Ki-67 score of 10% or less at the time of surgery.

People in these two groups received hormone therapy alone (no chemotherapy).

After five years, in the two groups that received hormone therapy alone:

- the overall survival rate was excellent and similar for both groups.
- survival rates did not differ by age or menopausal status.
- survival rates did not differ for people with 0 to 2 positive lymph nodes.
- people with 3 positive lymph nodes were more likely to have their cancer come back within 5 years (24%) compared to people with 0 positive lymph nodes (3%), 1 positive lymph node (5%) or 2 positive lymph nodes (8%).

This part of the ADAPT study showed that together, a patient’s Oncotype Dx score, Ki-67 scores and lymph node status may help identify women with up to three positive lymph nodes who can safely skip chemotherapy. Based on the results of the ADAPT study the following patients can be safely treated by hormone therapy alone:

- Patients treated with a short course of hormone therapy prior to surgery, 0 to 3 positive lymph nodes and Oncotype Dx scores of 0 to 11.
- Patients treated with a short course of hormone therapy prior to surgery, 0 to 2 positive lymph nodes, an Oncotype DX score of 12 to 25 and a Ki-67 tumor score of less than 10% at the time of surgery.

However, patients with hormone receptor-positive, Her2-negative breast cancer, Oncotype Dx scores between 12 to 25 and a Ki-67 score of 10 percent or less with three or more positive lymph nodes may not be good candidates for hormone therapy alone and may benefit from chemotherapy.
Strengths and limitations

- RxPONDER and ADAPT are both very large prospective, randomized studies.
- Follow-up for both studies has been limited. Data will continue to be collected and results may change.

What does this mean for me?

These results are likely to provide more clarity and guidance to doctors who recommend treatment for breast cancer patients who may be able to safely avoid chemotherapy. Many experts believe that national treatment guidelines may change based on the results of these studies.

If you are a premenopausal woman with estrogen receptor-positive, Her2-negative breast cancer, you should speak with your doctor about the possible benefits of chemotherapy. If you are a post-menopausal woman with estrogen-receptor-positive, Her2-negative breast cancer and have zero to three positive lymph nodes, an Oncotype DX test together with Ki-67 tests may help your doctor determine whether or not you will benefit from chemotherapy.

Share your thoughts on this XRAYS article by taking our brief survey posted 3/4/21.

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WHO COVERED THIS STUDY?

verywellhealth
Chemotherapy may not be necessary for certain breast cancers, study finds★★★★★

Cancer Therapy Advisor
Adjuvant endocrine therapy alone judged suitable for certain breast cancer patients★★★★★

Medscape
RxPONDER: Chemo 'no longer a mandate' for some with breast cancer★★★★

How we rated the media

IN-DEPTH REVIEW OF RESEARCH

Study background

Historically, most patients with breast cancer who were hormone receptor-positive and node-negative received chemotherapy, but many may not have benefited from it. Tumor tests that may help predict an individual’s risk of recurrence and indicate those who would most benefit from chemotherapy are now available.

Oncotype DX is a test to predict whether chemotherapy will benefit a patient with hormone receptor-positive breast cancer. Recurrence scores are based on RNA expression of 21 genes. Recurrence scores range from 0 to 100.

The results of the TAILORx trial, the largest breast cancer treatment trial ever conducted, suggest that the Oncotype DX tumor test could identify up to 85 percent of women with early breast cancer who can forego adjuvant chemotherapy. This applies especially to women older than 50 who have a recurrence score of 25 or less and women 50 years of age or younger with a recurrence score of 15 or less. This trial was previously discussed in an XRAY review here.

While the TAILORx trial was groundbreaking, more studies were needed to clarify which women need more of some therapies and less of others. For example, it was uncertain which if any women with early-stage node-positive breast cancer could safely forgo chemotherapy.

Two studies presented at the 2020 San Antonio Breast Cancer Symposium attempted to answer this important question.

Researchers of these studies wanted to know if tumor tests could be used to identify more women who can safely forgo chemotherapy. Specifically, are there women with hormone receptor-positive, Her2-negative breast cancer who are candidates for chemotherapy by standard criteria who can safely be treated with hormone therapy alone?

The RxPONDER trial

https://www.facingourrisk.org/XRAY/skipping-chemotherapy
Can some breast cancer patients skip chemotherapy safely?

Populations looked at in this study

RxPONDER is a prospective, randomized trial of hormone therapy versus chemotherapy combined with hormone therapy in women with one to three positive lymph nodes and an Oncotype Dx score below 25. Eligible participants were women over 18 years of age with hormone receptor-positive, HER2-negative breast cancer with one to three positive lymph nodes.

Study design

A total of 9,383 women with HR-positive, Her2-negative breast cancer and one to three positive lymph nodes were screened to identify those with Oncotype Dx recurrences scores of 25 or less. Among those identified, 5,083 patients were randomly assigned to receive hormone therapy alone or hormone therapy plus several months of intravenous chemotherapy with taxane and/or anthracyclines. These chemotherapy drugs are considered to be standard treatments for this type of cancer.

The primary goal of the study was to determine the effect of chemotherapy on disease-free survival and whether the effect depended on Oncotype Dx scores. All women were monitored for about five years to assess invasive disease-free survival, or IDFS, a measure that counts which patients develop cancer that spreads outside of the breast, develop a new tumor inside a breast or die from any cause. Overall survival was a secondary assessment.

Study findings

As a data and safety monitoring committee began reviewing the trial results, they noticed a surprising pattern—one that was clear enough for them to recommend that the findings be reported publicly before the final analysis was complete.

Data from 5,015 participants were used in the early five-year analysis.

- Among postmenopausal women:
  - The five-year disease-free survival rate was 91.6% for the chemotherapy-plus-hormone therapy group and 91.9% for the hormone therapy-only group.

- Among premenopausal women:
  - The five-year disease-free survival rate was 94.2% for the chemotherapy-and-hormone therapy group, compared to 89.0% for the hormone therapy-only group.
  - Premenopausal women also had an overall survival benefit from chemotherapy.
    - At five years, the overall survival rate was 98.6% for those receiving chemotherapy plus hormone therapy and 97.3% for women in the hormone therapy-only group.

The ADAPT trial

Populations looked at in this study

Among the 5,625 registered participants, 2,290 women with hormone receptor-positive, Her2-negative breast cancer who were candidates for chemotherapy by standard criteria were studied in the ADAPT hormone therapy arm.

Study design
The ADAPT trial looked at combining two tumor scores, Oncotype Dx and a tumor marker called Ki-67, to see if combining these scores could identify women with up to three positive lymph nodes who were most likely to benefit from chemotherapy. The study was done as follows:

- All patients had a biopsy.
- Biopsy tissue was tested by Oncotype Dx to generate a recurrence score and tested to see what percentage of tumor cells had the Ki-67 tumor marker.
- All patients had a short course (about 3 weeks) of hormone therapy before surgery.
- After surgery, patients’ tumors were again scored for Ki-67.
  - If the second Ki67 score was less than 10% (less than 10% of tumor cells had the Ki-67 tumor marker), the researchers used that as an indication that patients were responding to hormone therapy.
- Researchers grouped patients by Oncotype Dx and their second Ki-67 score. The two groups that received hormone therapy alone were:
  - those who had an Oncotype Dx score of 0 to 11 (868 participants) and had a Ki-67 score of less than 10% at the time of surgery.
  - those who had an Oncotype Dx score of 12 to 25 (1,422 participants) and had a Ki-67 score of less than 10% at the time of surgery.
- Women with Oncotype Dx scores of 12 or higher and Ki67 scores of 10% or higher after 3 weeks of hormone therapy were given chemotherapy with hormone therapy after surgery. The results of this group were presented in another presentation and are not included here.

**Study findings**

After 5 years:

- The overall survival rate was excellent and similar for both groups.
  - Patients with Oncotype Dx scores of 0 to 11 had a 5-year survival rate of 98%.
  - Patients with Oncotype Dx scores of 12 to 25 who were responding to hormone therapy had a 5-year survival rate of 97%.
- Survival rates did not differ by subgroup such as age or how many positive lymph nodes a patient had except for one subgroup of women with 3 positive lymph nodes.
  - Patients in this subgroup with recurrence scores of 12 to 25 who responded to pre-surgery hormone therapy had a significantly lower 5-year disease-free survival rate of 76% compared to patients with no positive lymph nodes (97%), 1 positive lymph node (95%) or 2 positive lymph nodes (92%).
- The ADAPT study showed that regardless of age, the following patients can be safely treated by hormone therapy alone:
  - Patients with 0 to 3 positive lymph nodes and Oncotype Dx scores of 0 to 11.
  - Patients with 0 to 2 positive lymph nodes and Oncotype Dx scores of 12 to 25 who are responding to hormone therapy based on Ki-67 tumor scores of 10% or lower.
- The ADAPT study also suggests that patients with 3 positive lymph nodes who had Oncotype Dx scores of 12 to 25 and responded to hormone therapy based on Ki-67 tumor scores may not be good candidates for hormone therapy alone and may benefit from chemotherapy.

Looking at Oncotype Dx scores score together with Ki-67 scores may help identify women who can safely skip chemotherapy.
Why are study results different?
The results of RxPONDER and the ADAPT studies seem to be different based on menopausal status and the number of positive lymph nodes.

- RxPONDER showed that postmenopausal women with up to 3 positive lymph nodes do not benefit from chemotherapy.
- ADAPT showed that regardless of menopausal status, women with 3 positive lymph nodes likely benefit from chemotherapy.

These differences are likely due to how the two studies were conducted. Both studies looked at Oncotype Dx scores in patients with early breast cancer and 0 to 3 positive lymph nodes.

However, patients in the ADAPT study had:

- a short course of hormone therapy before surgery (patients in the RxPONDER study did not).
- a Ki-67 tumor score at biopsy and at surgery. This score was used to identify patients for whom hormone therapy seemed to be working. (Ki-67 scores were not used in RxPONDER so researchers did not identify which patients might not respond to hormone therapy.)

Strengths and limitations

Strengths

- RxPONDER and ADAPT are both very large prospective, randomized studies.

Limitations

- To date, follow-up for both studies is limited. Data will continue to be collected and results may change.

Context

The side effects of chemotherapy can be devastating. While some resolve quickly, others may last months, years or even a lifetime. The results of the RxPONDER and ADAPT studies are likely to be useful in the clinic and expand the number of patients who can safely forgo chemotherapy.

Conclusions

These studies represent important steps towards the goal of more personalized medicine. By matching patients to the treatments that will likely benefit them, doctors can also identify patients which are unlikely to benefit from treatments.

Share your thoughts on this XRAYS article by taking our brief survey.

posted 3/4/21

https://www.facingourrisk.org/XRAY/skipping-chemotherapy
Study: Early research on a drug to prevent breast cancer

SUMMARY

Many researchers are interested in non-surgical options to reduce the higher-than-average risk of developing breast cancer in BRCA mutation carriers. This research study identified a type of drug, called a “RANK ligand inhibitor,” that may prevent breast cancer. Among mice that were genetically engineered to have no BRCA1 genes, those that were given the drug developed tumors less frequently than those that did not. While this is an exciting early study for BRCA mutation carriers, more work and human clinical trials need to be done before this can be used as a prevention therapy in humans. (7/12/16)

Update added 11/24/19: The RANK ligand inhibitor, denosumab is currently being studied as a possible breast and ovarian cancer preventive agent in human clinical trials.
Whether inhibiting a potential new target (RANK ligand) can help prevent breast cancer in BRCA1 ( ) mutation carriers.

**Why is this study important?**

Women who carry a BRCA1 mutation have an approximately 65% risk of developing breast cancer by the time they are 70 years old, and they often develop more aggressive tumors at an earlier age than women who do not have mutations. To lower their breast cancer risk, BRCA1 carriers can opt to undergo prophylactic mastectomy or take risk-reducing medications such as tamoxifen or raloxifene. However, no current medication reduces breast cancer risk as much as surgery.

**Study findings:**

1. Mice that were genetically engineered to have no BRCA1 genes and were given a drug known as a RANK ligand inhibitor developed fewer breast tumors compared to mice that were not given the drug.

**What does this mean for me?**

This interesting early work suggests drugs that inhibit RANK ligand might prevent breast cancer in BRCA1 carriers. However, more work needs to be done before inhibiting RANK ligand becomes an established method of prevention—drugs that work well in mice don’t necessarily work well for humans. Mice can be used to model a human disease, but differences between the species means that drugs that work in one do not always work in the other.

Some media outlets called the RANK ligand inhibitor drug the ‘holy grail’ of breast cancer prevention for BRCA1 mutation carriers. But these headlines are misleading and inaccurate because this study was only done in mice and cells grown in the lab. Clinical trials need to determine whether this drug works for humans. BRCA1 mutation carriers should talk to their health care providers to determine which method of breast cancer risk reduction they are most comfortable with.

Posted 7/12/15

Share your thoughts on this XRAY review by taking our brief survey.

**References**


Health News Review. “**It's never OK to use 'holy grail of breast cancer prevention' when talking about pre-clinical animal study.**”

**Disclosure**

https://www.facingourrisk.org/XRAY/breast-cancer-prevention-drug
FORCE offers many peer support programs for people with inherited mutations.

- Our Message Boards allow people to connect with others who share their situation. Once you register, you can post on the Diagnosed With Cancer board to connect with other people who have been diagnosed.
- Our Peer Navigation Program will match you with a volunteer who shares your mutation and situation.
- Our moderated, private Facebook group allows you to connect with other community members 24/7.
- Check out our virtual and in-person support meeting calendar.
- Join a Zoom community group meeting.
  - LGBTQIA
  - Men
  - American Sign Language
  - People of Color

Updated: 02/05/2022

WHO COVERED THIS STUDY?

Cancer Research UK
Lab study ‘sheds new light’ on BRCA-linked breast cancer

Medical News Today
Breast cancer: Existing drug shows promise for prevention in high-risk women

CNN
Unlikely drug may block breast cancer in high-risk women

Independent
Breast cancer treatment ‘holy grail’ within reach after breakthrough, scientists claim

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
BRCA1 mutation carriers are predisposed to developing breast cancer that is more aggressive and occurs earlier than breast cancer in the general population. Women with BRCA1 mutations are counseled to undergo one or more risk management strategies, such as increased screening, which does not prevent cancer but can catch it at an earlier stage; risk-reducing medication; and/or risk-reducing surgeries. While these strategies have helped many women reduce their risk of cancer, there is still a need for better nonsurgical means of cancer prevention in BRCA1 mutation carriers.

Researchers of this current study explored the use of a type of drug known as a RANK ligand inhibitor for breast cancer prevention in BRCA1 mutation carriers. Emma Nolan and her colleagues at the Walter and Eliza Hall Institute of Medical Research and other institutions published research in Nature Medicine that explores what happens when RANK ligand is inhibited.

**Researchers of this study wanted to know:**
Can inhibiting RANK ligand be used as a method for breast cancer prevention in BRCA1 mutation carriers?

**Population(s) looked at in the study:**
This research used a number of different laboratory models of breast cancer.

- For some of the experiments, the researchers used breast tissue from 33 premenopausal women undergoing breast reduction surgery (used as the ‘wild type’ control) and 24 BRCA1 mutation carriers undergoing prophylactic mastectomies (Study Findings #3 and #4).
- They also used human breast tumors from the Amgen Tissue Bank cohort in one of their experiments (Study Findings #1 and 2).
- For the remainder of the experiments (Study Finding #5), researchers used mice that were genetically engineered to have no BRCA1 genes in their breast tissue (these mice have been shown to develop breast cancers that are similar to human breast cancer). Note that differs from humans, who have one defective and one healthy BRCA1 gene.

**Study findings:**

1. RANK ligand, the target of the drug in this study, is found in much higher levels in BRCA1-mutated tumors compared to tumors with normal BRCA1.
2. RANK ligand was not found in significantly higher levels in BRCA2-mutated breast tumors.
3. Breast tissue cells from BRCA1 patients that had the RANK ligand formed tumors more easily in the laboratory than cells from the same BRCA1 patients that did not have the RANK ligand.
4. BRCA1-mutated cells that had the RANK ligand were more sensitive to DNA damage than BRCA1-mutated cells that did not have the RANK ligand.
5. Mice that were genetically engineered to have no BRCA1 genes and were given the RANK ligand inhibiting drug developed fewer breast tumors compared to the control mice, which were also BRCA1 mutated but were not given the inhibitor.
   - 11 of 17 mice given the RANK ligand inhibitor did not develop tumors by the researchers’ chosen end date for the experiment.

**Limitations:**

https://www.facingourrisk.org/XRAY/breast-cancer-prevention-drug
While the results are interesting, this is primarily a mouse study with some data in human cells to back it up. More work needs to be done to translate these findings to the clinic, particularly clinical trials to show that the drug is safe for long-term use and effective in preventing breast cancer. Additionally, the mice used in the experiment with the RANK ligand inhibitor were genetically engineered to have no BRCA1 genes. This is different than humans with BRCA1 mutations, who start off with one good copy of BRCA1 (out of the two that they inherited from their parents).

**Conclusions:**

The results of this study suggest that inhibiting RANK ligand may help prevent breast cancer in mice with BRCA1 mutations. More work needs to be done before this can be used as a breast cancer prevention therapy in BRCA1 mutation carriers. FORCE agrees with the Health News Review critique that media reports using the term “holy grail” to describe this early study were misleading. However, this is still an important first step towards developing a new option for BRCA1 mutations carriers who wish to delay or avoid risk-reducing surgery.

For now, women who are interested in new risk-reducing measures that do not involve surgery should talk to their health care provider about participating in clinical trials for breast cancer prevention in high-risk women or use our hereditary cancer research database to find clinical research studies that are enrolling people affected by hereditary cancer.

Posted 7/12/15

Share your thoughts on this XRAY review by taking our brief survey.

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**SEARCH XRAY STUDIES AND ARTICLES**

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**Categories:**

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure

https://www.facingourrisk.org/XRAY/breast-cancer-prevention-drug
Study: Racial disparities in BRCA testing: Why?

SUMMARY

Black women receive BRCA testing less frequently than white women. Why is that? Researchers thought the reason might be that black and white women see different health care providers. However, new research suggests that disparities in physician recommendations for testing are the cause: black women with breast cancer were less likely to receive physician recommendations for BRCA testing than white women with breast cancer. There is a need to ensure equity in physician testing recommendations for black women. (7/21/16)
Black women have a similar, if not higher chance of carrying a BRCA mutation than non-Jewish white women. Yet studies show that fewer black women have BRCA testing. Researchers do not understand why this disparity exists.

**Study findings:**

1. Black women with breast cancer were less likely than white women to have BRCA testing.
   - About one-quarter of black women had BRCA testing, compared to almost one-half of white women.

2. Black women with breast cancer were less likely to report positive attitudes about BRCA testing and were more likely to report negative attitudes.

3. The care of black and white women with breast cancer is highly segregated across surgeons and oncologists.
   - Oncologists and surgeons who cared for most black patients were younger and more likely to be female.

4. A physician recommendation was strongly associated with BRCA testing. For unknown reasons, surgeons and oncologists were about 1.5 times less likely to recommend BRCA testing to their black patients than their white patients.
   - Surgeons and oncologists who took care of more black patients did not differ in their attitude towards BRCA testing compared to surgeons and oncologists who saw more white patients.
   - Characteristics (age, sex, U.S.-trained, employment type, and when they graduated from medical school) of surgeons and oncologists did not explain the racial disparity in BRCA testing recommendation between black and white women.

**What does this mean for me?**

This study suggests that black women are less likely to get BRCA testing, possibly because their health care providers are less likely to recommend it, even though black women are as likely (if not more likely) to carry a BRCA mutation than white non-Jewish women. Health care providers should work to ensure that they communicate genetic service recommendations to all high-risk women, regardless of their race. Black women who are concerned about breast cancer in their families should ask their health care providers if genetic counseling or genetic testing is appropriate for them.

Posted July 21, 2016

Share your thoughts on this XRAYS article by taking our brief survey.
WHO COVERED THIS STUDY?

Breastcancer.org
Black women less likely to have genetic testing than white women, but not because they see different doctors
⭐⭐⭐⭐⭐⭐

Oncology Nurse Advisor
BRCA1/2 testing recommendations vary between black and white patients⭐⭐⭐⭐⭐⭐

How we rated the media

IN DEPTH REVIEW OF RESEARCH

https://www.facingourrisk.org/XRAY/racial-disparities-in-BRCA-testing
Study background:

Black and White non-Jewish/non-Hispanic women have similar chances of carrying a BRCA mutation. A recent study suggests that young black women with breast cancer are about twice as likely to carry a BRCA mutation compared to non-Hispanic white women. However, many studies have shown that black women do not get tested for BRCA as often as white women do. Researchers do not understand why this racial disparity exists.

When researchers of this study explored a possible explanation for this disparity, they noted that racial groups could be segregated unevenly in U.S. cities, suggesting that black women and white women may not be seeing the same healthcare providers. Anne Marie McCarthy and her colleagues at Harvard Medical School and other institutions published research in the Journal of Clinical Oncology to determine if black and white women are seeing different types health care providers and whether or not this accounts for the racial disparity in BRCA testing.

Researchers of this study wanted to know:

Why are black women not receiving BRCA testing as often as white women?

Population(s) looked at in the study:

The women in this study were between 18-64 years old, from Florida and Pennsylvania, and were diagnosed with localized or invasive breast cancer between 2007-2009. A total of 3,016 women (69% white and 31% black) were surveyed, with a response rate of 61%. Physicians were also surveyed; their response rate was 29% (808 oncologists and 732 surgeons).

Study findings:

1. The care of black and white women with breast cancer is highly segregated across surgeons and oncologists.
   - Oncologists and surgeons who cared for the most black patients were younger and more likely to be female.

2. A physician recommendation was strongly associated with BRCA testing. For unknown reasons, surgeons and oncologists were about 1.5 times less likely to recommend BRCA testing to their black patients than their white patients.
   - Surgeons and oncologists who cared for more black patients did not differ in their attitude towards BRCA testing compared to surgeons and oncologists who saw more white patients.
   - The characteristics of the surgeons and oncologists (age, sex, U.S.-trained, employment type, and when they graduated from medical school) did not explain the racial disparity in BRCA testing recommendations between black and white women.

3. Black women with breast cancer were less likely than white women to have BRCA testing.
   - About one-quarter of black women had BRCA testing compared to almost one-half of white women.

Limitations:

While 61% of women who qualified for the study responded to the survey, the characteristics of the respondents, including age, race and year of diagnosis, differed from the women who did not respond. Black women were also less likely than white women to provide data about their physicians. Because this data was based on a survey, some bias could exist in the women’s answers. For example, women who were tested may have been more likely to remember that their physician recommended testing than women who chose not to undergo testing.
This was a population-based study, meaning that not all the women involved met guidelines for genetic testing—the results might be different if study participants included only women who met guidelines for genetic testing. Additionally, researchers could not compare women who received care at academic centers versus non-academic centers. This study only looked at oncologists and surgeons. Other types of doctors could be involved, although in the researchers’ experience, few patients receive breast cancer care from health care providers other than oncologists and surgeons.

Finally, this study included only women from Florida and Pennsylvania. The researchers state that while those populations are large and diverse, it is possible that the patterns in those states are not the same as what may be seen in other areas in the U.S.

**Conclusions:**

This study suggests that although black and white women do not see the same health care providers (some providers see more black women than white and vice versa because of the area in which they practice), that does not explain why black women have BRCA testing less often than white women. This study did reaffirm that fewer black women are receiving recommendations to get BRCA testing than white women. The researchers suggest this may be because family cancer history information may be less complete among black women. This could stem from either less awareness of cancer diagnoses in other family members, or healthcare providers not asking about family history as often for black women as they do for white women. Even though black women have a similar, if not higher chance of carrying a BRCA as a non-Jewish white women, when researchers applied the 2007 BRCA risk assessment guidelines to their study population, they found that a lower proportion of black women were classified as “high risk” compared to white women. Using the current criteria, which includes women diagnosed with breast cancer before age 45 (previous guidelines included patients before age 40) and women with triple-negative breast cancer before age 60, might increase the number of black women who would meet national guidelines for testing.

Because the study did not include discussion about genetic counseling, it is unknown whether these patients saw genetic counselors, and whether seeing a genetic counselor increased genetic testing.

Ultimately, more work needs to be done to understand why this racial disparity in BRCA testing between black and white women exists. Until then, healthcare providers should be more conscious to fully assess BRCA risk for black women, who should question their health care providers if they believe they may be at genetic risk for breast cancer.

Posted July 21, 2016

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/racial-disparities-in-BRCA-testing).
Study: Extending aromatase inhibitor duration to 10 years lowers recurrence for ER/PR+ breast cancer patients

SUMMARY

Hormonal therapy reduces the risk of recurrence for women with early-stage breast cancer that is ER-and/or PR-positive. Standard therapy lasts 5 years. A new study looks at whether extending one type of hormonal therapy, known as aromatase inhibitor therapy, to 10 years lowers recurrence rates even more for these women. (7/26/16)
Whether patients will benefit (lower risk of recurrence or new breast cancer in the other breast) if they stay on aromatase inhibitor therapy for 10 years rather than the standard 5 years.

**Why is this study important?**

According to the lead author of this research study, patients with early-stage breast cancer live for a long time, but “face an indefinite risk of relapse.”

**Study findings:**

1. When the study ended, 95% of women who had 10 years of aromatase inhibitor therapy (Letrozole) had disease-free survival (meaning they did not develop a recurrence or a new cancer in the other breast), while 91% of women who had 5 years of aromatase inhibitor therapy had disease-free survival at the study endpoint.

2. Women who took the aromatase inhibitor for 10 years compared to 5 had no benefit in overall survival.

**What does this mean for me?**

This data suggests that extending aromatase inhibitor therapy to 10 years instead of stopping it at 5 may improve patient outcomes. Women who were on aromatase inhibitor therapy for 10 years did not have recurrences or develop new cancers in the other breast, although the difference between the 5-year and 10-year groups was relatively low. Women on 10 years of aromatase inhibitors experienced more side effects related to bone density and fractures. Women should have a risk/benefit conversation with their healthcare providers to discuss if extending aromatase inhibitor therapy is right for them. Patients also need to consider the side effects of aromatase inhibitors and the cost of the drug.

Posted 7/26/16

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/).

**References**

Goss PE, Ingle JN, Pritchard K, et al, "Extending adjuvant () Letrozole for 5 years after completing an initial 5 years of Aromatase Inhibitor therapy alone or preceded by Tamoxifen in Postmenopausal Women with Early-Stage Breast Cancer: A Randomized () Phase III Open Label Trial." Presented by Paul Goss at the 2016 American Society of Clinical Oncology Meeting.


WHO COVERED THIS STUDY?

Clinical Oncology News
What Is the benefit of extending AIs beyond five years? ★★★★★

Washington Post
Extending anti-estrogen therapy to 10 years reduces breast-cancer recurrence, new cancers ★★★

The Guardian
Breast cancer drugs should be given for 10 years, study shows ★★★★☆☆

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Researchers of this current study explored whether extending the length of time women took the aromatase inhibitor provided additional benefit. Paul Goss and his colleagues at Massachusetts General Hospital and other institutions presented their data on this new clinical trial (MA.17R) at the 2016 American Society of Clinical Oncology Meeting. Their observations of what happens when women take an aromatase inhibitor for 10 years instead of 5 were also published in The New England Journal of Medicine.

This study follows previous research showing that taking an aromatase inhibitor (Letrozole) after 5 years of tamoxifen improved disease-free survival.

Researchers of this study wanted to know:
Whether patients who stay on an aromatase inhibitor for 10 years have fewer recurrences and develop fewer new breast cancers than patients who take aromatase inhibitors for 5 years.

Population(s) looked at in the study:
The study enrolled 1,918 postmenopausal women who had estrogen receptor (ER)- and/or progesterone receptor (PR)-positive, early-stage breast cancer.

Women in the study fell into 1 of 3 groups:

- One group had received about 5 years of aromatase inhibitor (Al) therapy (Letrozole) in the researchers’ previous study, and took tamoxifen before Al therapy.
- The second group of women was not included in the previous study, and had received any of the 3 aromatase inhibitors currently in use for about 5 years, and took tamoxifen before Al therapy.
- The third group received about 5 years of any of the 3 current aromatase inhibitors currently in use, but never
took tamoxifen.

Among the 3 groups of women, some were randomized to receive another 5 years of AI therapy (Letrozole) or 5 years of receiving a placebo.

**Study findings:**

1. When the study ended, 95% of women who had 10 years of aromatase inhibitor therapy (Letrozole) had disease-free survival (meaning they did not develop a recurrence or a new cancer in the other breast), while 91% of women who had 5 years of aromatase inhibitor therapy had disease-free survival at the study endpoint.
   - In total, 67 patients who took Letrozole for 10 years developed a recurrence of cancer in the other breast, compared to 98 patients who took Letrozole for 5 years.

2. Women who took an aromatase inhibitor for 10 years had no additional benefit in overall survival compared to those who took an aromatase inhibitor for 5 years.

3. Patients who took Letrozole for 10 years were more likely to develop bone fractures than the patients who took it only for 5 years (14% versus 9%).

**Limitations:**

This research did not take genetic status into account, so how women with mutations in BRCA() or other genes that increase cancer risk respond to an additional 5 years of aromatase inhibitor therapy is unknown. Some patients involved in the study had previously taken tamoxifen, while some had not. From the data presented, it is not known if the use of tamoxifen before an aromatase inhibitor affected a patient’s risk of recurrence or new cancer. Finally, a number of aromatase inhibitors are available, and not all women in the study took the same aromatase inhibitor for the first 5 years.

**Conclusions:**

The results of this study suggest that taking an aromatase inhibitor for 10 years instead of 5 may benefit ER- and/or PR-positive breast cancer patients. But there was no increase in overall survival between women who took aromatase inhibitors for 5 years and those who took aromatase inhibitors for 10 years. Patients should discuss with their health care provider all the risks and benefits when thinking about extending their aromatase inhibitor for longer than 5 years.

Posting 7/26/16

Share your thoughts on this XRAYS article by taking our brief survey.
Exercise improves memory in survivors of early-stage breast cancer

Study: Is there a link between exercise and memory in breast cancer survivors?

SUMMARY

Exercise has many health benefits, but can it also help improve memory for breast cancer survivors? This research finds that breast cancer survivors who exercised more had less fatigue and distress (anxiety, depression, stress, and/or concern about recurrence) and scored better on memory tests. (8/2/16)

STUDY AT A GLANCE

This study is about:

Whether exercise helps memory impairment in breast cancer survivors.

This article is relevant for:

☑ People diagnosed with early stage breast cancer

This article is also relevant for:

☑ People with breast cancer
☑ Women under 45
☑ Women over 45
**Why is this study important?**

Breast cancer survivors frequently report experiencing memory impairment, which is linked to depression, anxiety, and fatigue. In this study, the researchers wanted to know how exercise is related to memory impairment, and its effects in breast cancer survivors.

**Study findings:**

1. Breast cancer survivors who exercised more had less fatigue and distress (anxiety, depression, stress, and/or concern about recurrence) and scored better on memory tests.

**What does this mean for me?**

The researchers propose a model where more exercise leads to less fatigue and distress, which results in less memory impairment for breast cancer survivors. More work needs to be done to confirm the link between exercise and memory impairment.

Exercise provides many health benefits. According to the Centers for Disease Control (CDC), exercise helps people to reduce their risk of cardiovascular disease and type 2 diabetes, reduce their risk for some cancers, increase their chances of living longer, and strengthen bones and muscles, among other things. Breast cancer survivors experiencing memory impairment and its associated distress and fatigue should talk to their health care providers to see what other things they can do to improve their symptoms.

Posted 8/2/16

Share your thoughts on this XRAYS article by taking our brief survey.

**Reference**


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
The following organizations have resources related to treatment side effects.

- FORCE related resources:
  - Information: [Chemotherapy side effects](#)
  - Information: [Hormone therapy side effects](#)
  - Information: [Immunotherapy side effects](#)
  - Information: [Radiation side effects](#)
  - Information: [Surgery side effects](#)
  - Information: [Targeted therapy side effects](#)
  - Information: [Wellbeing and survivorship](#)

- XRAY category: [Side effects](#)

- [FDA](https://www.fda.gov) MedWatch [online side effect reporting form](#)
- [National Cancer Institute](https://www.cancer.gov) [page on cancer treatment side effects](#)
- [Centers for Disease Control](https://www.cdc.gov) [page on cancer treatment side effects](#)
- [HairToStay](https://www.hairtostay.com) helps cancer patients cover the cost of scalp cooling.
- [Unite for Her](https://www.uniteforher.org) provides financial support for services that help improve quality-of-life in people diagnosed with breast or ovarian cancer.

**WHO COVERED THIS STUDY?**

**The Chicago Tribune**

*Exercise linked to fewer memory problems in breast cancer survivors* 🌟🌟🌟🌟🌟

**Tech Times**

*Exercise may improve stress-related memory problems in breast cancer survivors* 🌟🌟🌟🌟🌟

**Oncology Nurse Advisor**

*Moderate-to-vigorous exercise improves subjective memory in breast cancer survivors* 🌟🌟🌟🌟🌟

**US News & World Report**

*Why breast cancer survivors should exercise* 🌟🌟🌟🌟🌟

[How we rated the media](https://www.facingourrisk.org/XRAY/exercise-and-memory-in-survivors)
IN DEPTH REVIEW OF RESEARCH

Study background:
Cancer survivors experience a number of long-term side effects that can range from physical problems to psychological and emotional issues. Researchers previously studied how memory impairment affects anxiety, depression and fatigue in breast cancer survivors. In this study, they looked at how lifestyle choices such as regular exercise affect memory impairment and the symptoms associated with it.

In the July 2016 edition of the journal *Psycho-Oncology*, Siobhan Phillips and her colleagues from Northwestern University and the University of Illinois Urbana Champaign published their work about the relationship between exercise and memory impairment.

Researchers of this study wanted to know:
Can exercise help ease the symptoms associated with memory impairment (fatigue, anxiety, and/or depression) for breast cancer survivors?

Population(s) looked at in the study:
The study followed 1477 women. The women were at least 18-years-old, had been diagnosed with breast cancer, were English speaking, and had completed treatment for their cancer. The majority of the women were white (about 97%) and were diagnosed with ductal carcinoma in situ (DCIS) or early-stage (stage 1 or stage II) disease.

When women enrolled in the study they took surveys that evaluated their level of physical activity, distress, fatigue, and memory impairment. They then took the same survey 6 months later. A random subset of the participants wore accelerometers to measure their activity.

Study findings:
1. Breast cancer survivors who exercised more had less fatigue and distress (anxiety, depression, stress, and/or concern about recurrence) and scored better on memory tests.
   - Breast cancer survivors who exercised more had higher “exercise self-efficacy” meaning they believed that they would be able to exercise either three or five times each week.
   - Breast cancer survivors who had high exercise efficacy had lower levels of fatigue and distress (depression, concerns about recurrence, perceived stress, anxiety).
   - Breast cancer survivors who had low fatigue and distress scored higher on the Frequency of Forgetting test (which included questions such as where participants had put things, directions, and names), meaning they had less memory impairment than women who had high fatigue and distress.

Limitations:
The study population of this research study was mostly white (about 97%), highly educated and had high annual household income. Because of this, the results of this study may not hold true for all women. Additionally, the researchers only had one follow-up after 6 months. More work should be done to extend this time period.

Memory impairment can also be affected by many factors in addition to exercise, so more work should be done to include diet and other psychosocial factors.
Finally, because this study used participants’ self-reported results, their reporting could be biased. Future studies should be done that include objective measures of cognitive functioning (the researchers only looked at the relationships between exercise and anxiety/fatigue, and the relationship between anxiety/fatigue and memory impairment—they did not look at cognitive function directly after exercise). Additionally, among women who had less fatigue/anxiety, it was not determined whether that was because they exercised more.

**Conclusions:**

The results of this study suggest that exercise may be beneficial for memory impairment in breast cancer survivors. More work needs to be done to study this relationship; however, breast cancer survivors who are not exercising should work with a health care professional to create an exercise plan, as there are many established benefits to exercising.

Posted 8/2/16

Share your thoughts on this XRAYS article by taking [our brief survey](https://www.facingourrisk.org/XRAY/exercise-and-memory-in-survivors).

### SEARCH XRAY STUDIES AND ARTICLES

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- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing
- Health Disparities
- Health Literacy
- Hereditary Cancer
- Intimacy & Body Image

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https://www.facingourrisk.org/XRAY/exercise-and-memory-in-survivors
Study: Can acupressure be used to treat cancer-related fatigue?

SUMMARY

Breast cancer survivors commonly report experiencing considerable fatigue, which can lead to sleep problems and poor quality of life. Yet, there are no good therapies for these patients. This research study looks at whether self-administered acupressure can help breast cancer survivors with their fatigue. (8/9/16)
Breast cancer survivors commonly experience fatigue, which can lead to poor sleep and quality of life, yet few treatments are available.

**Study findings:**

1. Some breast cancer survivors who used acupressure had less fatigue over a 10-week period than breast cancer survivors who did not use acupressure.

**What does this mean for me?**

This study suggests that acupressure, which uses firm finger pressure to stimulate the same sensitivity points used in acupuncture, may be used for treating fatigue in breast cancer survivors. However, not all breast cancer survivors who used acupressure benefited from it. More work needs to be done to determine which patients might benefit most from acupressure, and how long patients should use it. Breast cancer survivors experiencing cancer-related fatigue should talk to their health care providers to see if acupressure is an option they might explore, and to find out what other options are available.

Posted 8/9/16

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**References**


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYs articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
IN DEPTH REVIEW OF RESEARCH

Study background:
About one-third of breast cancer survivors report experiencing moderate to severe fatigue after breast cancer treatment. In some cases, this fatigue can last up to 10 years! Finding ways to combat this fatigue is critical, as it affects quality of life. Even though fatigue is a major issue for some breast cancer survivors, few therapeutic options are available.

Suzanna Zick and her colleagues from the University of Michigan published work in the journal *JAMA Oncology* in July 2016 that examined acupressure as a potential treatment for persistent fatigue in breast cancer survivors.

Researchers of this study wanted to know:
Can relaxing acupressure or stimulating acupressure help breast cancer survivors with their persistent cancer-related fatigue?

Population(s) looked at in the study:
The women in this study were recruited from the Michigan Tumor Registry, with data collected from women who live in Michigan. These women previously had breast cancer between stages 0 to III, completed their cancer treatments 12 months prior to the study, and were currently cancer free. All women in the study scored 4 or higher on the Brief Fatigue Inventory (BFI), which assesses the severity and impact of cancer-related fatigue. Scores on the BFI range from zero (no fatigue) to 10 (as bad [fatigue] as you can imagine). Women who had a cancer diagnosis other than breast or skin cancer in the past 10 years, an untreated major depressive disorder, another diagnosed condition associated with fatigue, or who had previously done acupressure were not included in the study.

Study participants included 270 women, each randomly assigned to one of three groups:
- 94 women received relaxing acupressure
90 women received stimulating acupressure
86 women received only usual care—any treatment for fatigue that they were already receiving from their health care providers.

The women who received the acupressure treatments were taught by a trained acupressure educator to self-administer the therapy. They were assessed to see how well they performed the acupressure (for example, if they could locate the correct acupoints) at their first visit and at weeks 3 and 6.

**Study findings:**

1. A score of less than 4 on the Brief Fatigue Inventory (BFI) is considered normal for fatigue levels. After doing acupressure or usual care once daily for 6 weeks:
   - about 66% of breast cancer survivors who did relaxing acupressure had a BFI score of less than 4
   - about 61% of women who did stimulating acupressure had a BFI score of less than 4
   - about 30% of women who did usual care had a BFI score of less than 4

2. The women stopped doing the acupressure after 6 weeks. Their BFI scores were assessed again at 10 weeks to see if the effects of acupressure remained. At 10 weeks:
   - about 56% of breast cancer survivors who did relaxing acupressure had a BFI of less than 4
   - about 61% of women who did stimulating acupressure had a BFI of less than 4
   - about 30% of women who did usual care had a BFI score of less than 4

3. At week 6, women who did relaxing acupressure saw an improvement in their sleep quality compared to women who did usual care. However, that improvement did not persist once acupressure was stopped.

4. Women who did stimulating acupressure did not see any improvement in sleep quality.

5. At weeks 6 and 10, women who did relaxing acupressure had a better quality of life compared to women who had usual care.

6. Women who did stimulating acupressure did not see any improvement in quality of life.

**Limitations:**

The majority (about 90%) of women who participated in this study were white non-Hispanics; the majority of the minority women were black women. Because this study did not observe how male breast cancer survivors or people with metastatic breast cancer respond to acupressure, these findings may not be applicable to all breast cancer survivors. Additionally, this study looked only at doing acupressure for 6 weeks and only measured its effects after 10 weeks; researchers do not know how well the effects might hold up beyond 10 weeks. Six women could not complete the study because of bruising or difficulty doing the acupressure. And while the women were assessed to see how well they performed the acupressure, the therapy was self-administered, which means that the women’s techniques may have varied, and that they may have not adhered perfectly to the recommended daily schedule.

Finally, as pointed out in a PLOS blog post by James Coyne, a professor of health psychology, this was a single blind trial, which means that the patients’ health care providers knew which treatment they were getting, which could potentially bias how they were treated by their health care provider. And while the patients technically did not know which treatment they were getting, it would be obvious to the patients if they were getting the control treatment (no acupressure). More work should be done to see which breast cancer survivors are more likely to benefit from acupressure.
Conclusions:

The results of this study suggest that acupressure may be a therapeutic option for breast cancer survivors experiencing persistent cancer-related fatigue. According to the study authors, “Self-administered relaxing acupressure could offer an inexpensive, easy-to-learn intervention for improving fatigue, sleep, and quality of life in fatigued breast cancer survivors.” However, more work needs to be done to explore these findings further. These findings have not changed clinical guidelines—acupressure is not guaranteed to improve fatigue for breast cancer survivors. Patients should discuss with their health care providers to see if acupressure would be a good option for them.

Posted 8/9/16

Share your thoughts on this XRAYS article by taking [out brief survey](https://www.facingourrisk.org/XRAY/acupressure-and-cancer-related-fatigue).
Study: Does IVF increase a woman’s risk for breast cancer?

SUMMARY

In vitro fertilization (IVF) wasn’t commonly used until the 1980s, so its long-term effects are mostly unknown. A new study suggests that the treatment does not increase a woman’s risk for developing breast cancer. (8/23/16)
IVF use did not become common until the 1980s. Because of this, much is unknown about its long-term effects, including how it affects breast cancer risk.

**Study findings:**

1. The number of breast cancer cases that occurred in women who had IVF was similar to:
   - The number of breast cancer cases that occurred in women who did not have IVF (but had a different fertility treatment)
   - The number of breast cancer cases that would be expected in women in the general population.

**What does this mean for me?**

This study suggests that IVF treatment does not increase a woman’s risk for developing breast cancer. However, because most of the study population was younger than age 60, more work needs to be done to see whether or not postmenopausal breast cancer risk is increased after IVF. Patients who are having trouble conceiving and are considering IVF should talk to their healthcare provider.

Posted 8/23/16

Share your thoughts on this XRAY review by taking our brief [survey](https://www.facingourrisk.org/XRAY/ivf-and-breast-cancer-risk).

**References**


**Disclosure**

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IN DEPTH REVIEW OF RESEARCH

Study background:

The hormones estrogen and progesterone are known to affect breast cancer risk. Because the process of in vitro fertilization (IVF) temporarily alters the levels of these hormones, healthcare providers and researchers have expressed concerns about the effect of IVF on breast cancer.

Although other studies have looked at the effect IVF may have on breast cancer risk, many of these past studies had a short follow-up time after IVF, or did not compare breast cancer rates in women who had IVF to women who did not use IVF but were also having difficulty conceiving.

Alexandra van den Belt-Dusebout and her colleagues from the Netherlands Cancer Institute and other institutions published work in the July 2016 *Journal of the American Medical Association (JAMA)* that assessed the long-term risk of breast cancer for women who had IVF.

Researchers of this study wanted to know:

Does a woman’s breast cancer risk increase after undergoing IVF?

Population(s) looked at in the study:

The 25,108 women in this study were part of the Omega study cohort of women who were being treated for difficulty conceiving in IVF clinics in the Netherlands between 1980 and 1995. The group included 19,158 women who had undergone IVF, whether or not it resulted in a successful pregnancy, and 5,950 women who underwent fertility treatments other than IVF, such as artificial insemination, tubal surgery, and other hormonal treatments. None of the women had cancer before their IVF treatment. Women in the study were followed for about 21 years after their IVF treatment to see if they developed breast cancer.
Study findings:

1. The number of women who developed breast cancer after IVF was not significantly different from the number of women who developed breast cancer, but not after having IVF. This suggests that IVF did not influence breast cancer risk:
   - 3% of women who underwent IVF developed breast cancer by age 55.
   - About 3% of women who did not undergo IVF (but had a different fertility treatment) developed breast cancer by age 55.

2. The number of women who developed breast cancer after IVF was not significantly different compared to the number of women who were expected to develop breast cancer in the general population.

Limitations:

This study is based of IVF treatment procedures used until 1995. Current IVF procedures differ slightly in the number and length of some cycles.

For most women in the study, the researchers did not know their age at menopause or menopausal status at the end of their follow up. The researchers stated that, “If IVF-treated women reach earlier menopause than women in the general population, breast cancer risk after IVF may have been underestimated.”

This study looked at women in the general population, and did not ask about the women’s family history of cancer or mutation status that might affect cancer risk, so we do not know if these results apply to carriers of BRCA or other mutations that increase breast cancer risk. However, these results are similar to a previous study done on breast cancer risk in BRCA mutation carriers who had IVF or took other fertility medications. But this study population was small, and the researchers emphasized the need to interpret their results with caution and to see if they could be confirmed with a larger study.

Conclusions:

The results of this study suggest that in vitro fertilization does not increase a woman’s risk of developing breast cancer. However, because of the limitations of the study, more work needs to be done in a population that includes postmenopausal women, so that researchers can assess postmenopausal breast cancer risk in women who use current IVF procedures and confirm these findings. Women who are having trouble conceiving should talk to their healthcare provider to determine what options are best for them.

Posted 8/23/16

Share your thoughts on this XRAY review by taking our brief survey.

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https://www.facingourrisk.org/XRAY/ivf-and-breast-cancer-risk
Study: How beneficial is online communication after a new diagnosis of breast cancer?

SUMMARY

Newly diagnosed breast cancer patients often use online communication to find more information about their diagnoses and treatment options. But does online communication benefit these patients’ decision-making process? (8/30/16)
Online communication between breast cancer patients can help with medical decision-making

STUDY AT A GLANCE

This study is about:
Whether online communication, including email, texting, social media such as Twitter and Facebook, and/or web-based support groups helps patients who are newly diagnosed with breast cancer make decisions about their treatment.

Why is this study important?
Little is known about how newly diagnosed breast cancer patients use online communication in their decision making process.

Study findings:
1. Newly diagnosed breast cancer patients who frequently used online communication were more satisfied with their decisions about treatment.

What does this mean for me?
This study suggests that using online communication can help newly diagnosed breast cancer patients view their treatment decision choices more positively. However, the researchers included many different forms of communication, from texting to web-based support groups, noting that the majority of usage in the study population was for texting and emailing. More work needs to be done to assess other communication methods to see if they positively affect newly diagnosed breast cancer patients.

Posted 8/30/2016

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The following organizations have resources related to mental and emotional health after a cancer diagnosis.

- FORCE related resources:
  - Information: [Emotional wellbeing](#)
  - XRAY category: [Emotional health](#)

- National Comprehensive Cancer Network information: [Distress During Cancer Care](#)

- [Cancer Support Community](#)
- [CancerCare](#)
- [Cancer Hope Network](#)

Updated: 12/06/2021

### WHO COVERED THIS STUDY?

**Medical Xpress**

_Do patients use online communications following a new breast cancer diagnosis?_ 🌟🌟🌟🌟🌟 🌟

**Health Imaging**

_Online communications aid new breast cancer patients, but usage gaps persist_ 🌟🌟🌟🌟🌟 🌟

**The Economic Times**

_How social media is helping breast cancer patients with treatment decisions_ 🌟🌟🌟🌟🌟 🌟

**Health Day**

_'Ppl. I have breast cancer'_ 🌟🌟🌟🌟🌟 🌟

**Medscape**

_Going online ups patients' satisfaction about tx decisions_ 🌟🌟🌟🌟🌟 🌟

How we rated the media

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**IN DEPTH REVIEW OF RESEARCH**

**Study background:**

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[https://www.facingourrisk.org/XRAY/benefit-of-online-communication](https://www.facingourrisk.org/XRAY/benefit-of-online-communication)
Patients can gain lots of information by communicating online with other breast cancer patients about their diagnoses and treatment options. But because little is known about how online communication affects how newly diagnosed breast cancer patients view their treatment decision choices, Lauren Wallner and her colleagues from the University of Michigan, Ann Arbor, and other institutions published a research letter in JAMA Oncology in July 2016 that examined online communication use by these patients during their treatment decision process.

Researchers of this study wanted to know:

Does online communication change how newly diagnosed breast cancer patients view their treatment decision choice?

Population(s) looked at in the study:

The 2,460 women in this study were between the ages of 20-79, and newly diagnosed with breast cancer (stages I-III) between July 2013 and September 2014. The researchers obtained information about these women through the Surveillance, Epidemiology, and End Results (SEER) registries of the state of Georgia and Los Angeles County. About 6 months after their breast cancer diagnosis, the women filled out surveys regarding their treatment experiences.

The survey asked:

1. how often the women used online communication (defined by the researchers as including email, texting, social media such as Twitter and Facebook, and/or web-based support groups) after their breast cancer diagnosis.
2. how satisfied the women were with their choice of treatment.

The majority (about 59%) of the women were white. Fewer (about 16%) were black, with Latina women (about 14%), and Asian women (about 8%) also included. The average age of women who took the survey was about 62.

Study findings:

1. About 41% of women reported that they had some or frequent use of online communication.
   - The most common (about 35%) form of communication used was email and texting.
   - About 12% of women used social media, and about 12% of women used web-based support groups.
2. White and Asian women used online communication the most (about 46% of white women and about 43% of Asian women).
3. Younger women (under age 50) with more education tended to use online communication more than older women.
4. Women who frequently use online communication were more likely to report that they were satisfied with their treatment decision.

Limitations:

The researchers grouped all forms of communication into one category, including texting, Twitter, and web-based support groups into one group. These methods of communication differ from one another—texting may occur with more intimate family members, while Facebook and Twitter may be used for communicating with people whom the women have never met before, but who are experiencing the same issues and feelings. These are all valuable methods of communication; however, it would be helpful to know how each one affects how patients view their decisions.
Online communication between breast cancer patients can help with medical decision-making. Additionally, because the researchers did not break up the group of women into different age categories, it is unclear which women benefited the most by their online communication. Nor did the researchers look at how online communication affects women at higher risk for breast cancer due to family history or mutations in cancer risk-increasing genes, or women who had metastatic breast cancer. Women with these diagnoses face a different set of decisions, and might have more difficulty finding someone who has faced similar decisions.

**Conclusions:**

The results of this study suggest that online communication may help newly diagnosed breast cancer patients view their decisions more positively. However, wide variation in the results across age and race indicated that some women may have barriers to access online communication. And while the study did look at patient satisfaction, it did not identify or assess the various treatments the women chose or how well these treatments worked for them. More work needs to be done to further understand how online communication impacts patients.

For those looking for online support, FORCE online one-on-one peer support through our Peer Navigator program. Our free program matches people considering genetic testing and/or facing hereditary cancer (a) with a trained volunteer who has experienced a similar journey.

**References**


**Disclosure**

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**https://www.facingourrisk.org/XRAY/benefit-of-online-communication**
Study: Rare mutations in PALB2, CHEK2, and ATM: how much do they increase cancer risk?

**SUMMARY**

As multi-gene panel tests become more common, people are discovering they have mutations in genes that are not understood as well as BRCA. This can make it difficult to give patients accurate assessments of their cancer risk. For example, mutations in PALB2, CHEK2, and ATM are rare, but some specific changes in these genes are even less common. The goal of this international collaboration was to better understand the cancer risks of some very rare PALB2, CHEK2, and ATM mutations. The findings are relevant only to the specific mutations covered in this paper and do not apply to all people with mutations in PALB2, CHEK2, or ATM. (9/27/16)
The breast, ovarian, and prostate cancer risks associated with rare mutations in PALB2, CHEK2, and ATM.

**Why is this study important?**

Some mutations in PALB2, CHEK2, and ATM are rare, making it difficult to determine the exact increased cancer risk for people who carry them. Patients with these mutations need to know this information so that they and their healthcare providers can make appropriate decisions about their cancer screenings and treatment.

**Study findings:**

1. **PALB2 mutations:** There were three rare PALB2 mutations studied.
   - Two were associated with an increased risk of breast cancer, and one was not.
   - None of the three rare PALB2 mutations studied were associated with increased prostate or ovarian cancer risk.

2. **ATM mutations:**
   - One rare ATM mutation was associated with an increased risk of breast cancer, but not with prostate or ovarian cancer.

3. **CHEK2 mutations:** There were six rare CHEK2 mutations studied.
   - Four were associated with increased breast cancer risk, although the risk was not as high as those found in some of the PALB2 and ATM mutations.
   - One mutation was not associated with increased breast cancer risk for European women, but was associated with increased prostate cancer risk for European men.
   - One mutation that was only found in African men and women was associated with both increased breast cancer and prostate cancer risk.
   - None of the six mutations were associated with an increased risk for ovarian cancer.

**What does this mean for me?**

It is important to remember that this study looked at just a handful of rare mutations in ATM, CHEK2 and PALB2, and cannot be used to draw conclusions about all mutations in these genes. However, this work indicates that it is important to know the exact mutation a patient has, as well as his/her personal and family history of cancer when developing a plan for cancer screening or assessing potential treatment options. More work needs to be done to confirm some of these findings, and to determine other rare mutations that may increase a patient’s cancer risk or not have an effect on a
patient’s cancer risk. Patients should work with their healthcare providers to understand their genetic test results and determine what screenings and treatments are best for them.

Posted 9/27/16

Share your thoughts on this XRAYS article by taking our brief survey.

References


The National Comprehensive Cancer Network (NCCN) provides guidelines for management of breast cancer risk in people with inherited mutations linked to breast cancer. We recommend that you speak with a genetics expert who can look at your personal and family history of cancer and help you to determine the best risk management plan.

ATM, BARD1() or CHEK2

- Beginning at age 40 (or earlier based on family history):
  - recommend annual mammogram() (consider 3D mammography(), if available).
  - consider annual breast MRI() with contrast.

BRIP1(), RAD51C() or RAD51D()

- No specific breast cancer screening guidelines. Risk management should be based on family history of cancer.

CDH1()

- Beginning at age 30 (or earlier based on family history):
  - recommend annual mammogram (consider 3D mammography, if available).
  - consider annual breast MRI() with contrast.
  - discuss risk reducing mastectomy.

PALB2

- Beginning at age 30 (or earlier based on family history):
  - recommend annual mammogram (consider 3D mammography, if available).
  - recommend annual breast MRI() with contrast.
  - discuss risk reducing mastectomy.
WHO COVERED THIS STUDY?

**Breast Cancer News**

*Rare genetic mutations tied to higher risk of breast cancer* 🌟🌟🌟🌟🌟

**News.com.au**

Also published in:
The same article was also covered by *Nine.com.au*

*Rare genes increase breast cancer risk* 🌟🌟🌟🌟🌟

**Medical Xpress**

*World-first study confirms rare genetic mutations cause high breast cancer risk* 🌟🌟🌟🌟🌟

How we rated the media

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**IN-DEPTH** (click to expand)

IN DEPTH REVIEW OF RESEARCH

**Study background:**

Many multi-gene panel tests look for mutations in PALB2, CHEK2, and ATM. However, while mutations in these genes are rare, some versions of the mutations are even less common. Our current understanding of cancer risk associated with mutations in PALB2, CHEK2, and ATM results from studying the most common mutations in these genes. From this past work, researchers realized that in some cases, mutations in PALB2 could increase cancer risk as much as a mutation in a *BRCA* gene, while mutations in CHEK2 and ATM increase cancer risk to a lesser extent but above the level of an average person.

Studying rare mutations is difficult because the study has to be large enough to see how mutations in these genes affect cancer risk. Yet researchers have a hard time finding enough people with these rare mutations to study cancer risk and draw conclusions that can be used to make cancer risk management decisions.

Melissa Southey and her colleagues from The University of Melbourne and other institutions around the world published work in the *Journal of Medical Genetics* in June 2016 that assessed the cancer risk associated with a handful of specific, very rare mutations in PALB2, CHEK2, and ATM.

**Researchers of this study wanted to know:**

What are the breast, ovarian, and prostate cancer risks associated with rare mutations in PALB2, CHEK2, and ATM?

**Population(s) looked at in the study:**

The participants in this study were from studies participating in three consortiums:

- The Breast Cancer Association Consortium (BCAC)
  - The majority of women in the studies from this consortium were of European ancestry (42,671 cases and 42,164 controls), compared to Asians (5,795 cases and 6,624 controls), and African Americans (1,046 cases...
and 932 controls). All of the women had invasive breast cancer.

■ The Prostate Cancer Association Group to Investigate Cancer Alterations in the Genome (PRACTICAL)
- The majority of men in the studies from this consortium were of European ancestry (22,301 cases and 22,320 controls), compared to African American men (623 cases and 569 controls).

■ The Ovarian Cancer Association Consortium (OCAC)
- The majority of women in the studies from this consortium were of European ancestry (16,287 cases and 14,542 controls), compared to Asian women (720 cases and 93 controls), and African American women (150 cases and 36 controls).

These consortiums are all part of the Collaborative Oncological Gene-environment Study (COGS) with a total of 176,873 participants.

Study findings:

1. PALB2 mutations: There were three rare PALB2 mutations studied.
   - Two mutations were associated with increased breast cancer risk (PALB2 c.1592delT and PALB2 c.3113G>A), while one was not (PALB2 c.2816T>G). In all, 41 people were found to have the PALB2 c.1592delT mutation, 52 people had the PALB2 c.3113G>A mutation, and 295 people had the PALB2 c.2816T>G mutation.
   - None of the three rare PALB2 mutations studied showed an association with increased prostate or ovarian cancer risk.

2. ATM mutations:
   - The one rare ATM mutation (ATM c.7271T>G) studied was found to be associated with an increased risk of breast cancer, but not for prostate or ovarian cancer; only 13 people in this study had this mutation.

3. CHEK2 mutations: There were six rare CHEK2 mutations studied.
   - Four mutations (CHEK2 c.349A>G, CHEK2 c.538C>T, CHEK2 c.715G>A, CHEK2 c.1036C>T) were associated with increased breast cancer risk, although the risk was not as high as the PALB2 and ATM mutations studied. The study showed that 62 people had the CHEK2 c.349A>G mutation, 300 people had the CHEK2 c.538C>T mutation, 24 people had the CHEK2 c.715G>A, and 11 people had the CHEK2 c.1036C>T mutation.
   - One mutation (CHEK2 c1312G>T) was not associated with increased breast cancer risk for European women, but was associated with increased prostate cancer risk for European men; 34 people in this study had this mutation.
   - One mutation (CHEK2 c.1343T>G) was only found in African men and women, and was associated with increased breast cancer and prostate cancer risk; 46 people in this study had this mutation.
   - None of the six mutations were associated with an increased risk for ovarian cancer.

Limitations:
The cancer risks calculated in this study apply to very few people because, of the hundreds of mutations that can occur in PALB2, CHEK2, and ATM, the study looked at only 10 specific mutations. Because these are rare mutations, the sample size for some of them was too small, even from an international collaboration, to yield a definitive conclusion (especially as seen in the mutations that were carried by less than 20 people). Additionally, the international approach does not greatly improve the risk estimates for the mutations that are only found in certain populations (such as the CHEK2 mutation that was only found in African American patients). This means that the
cancer risks calculated in this study might not apply to the few people who have one of these rare mutations. Finally, it is always important to remember mutation status is not the only measure of increased cancer risk. Even if a person has a mutation that was found to not increase cancer risk in this study, there are other factors that are involved in determining cancer risk including family history and lifestyle factors.

Conclusions:
The results of this study suggest that some of the rare mutations in PALB2 and ATM may be associated with increased risk of breast cancer, putting these women at "high risk." This indicates that these women should have more screening and should discuss risk-reducing measures with their health care providers. However, more work needs to be done, especially in developing more methods that can be used to estimate these risks accurately for these rare mutations that are difficult to study with human populations. This study is a clear example of how much work and how many research participants are needed to get reliable estimates of cancer risks associated with specific mutations.

It is important to note that this study looked at a handful of specific mutations in PALB2, CHEK2, or ATM; it did not look at the risk of having any mutation in these genes. People with mutations in PALB2, CHEK2, or ATM should consult with a genetics expert who can look at both their gene mutation as well as their personal and family history of cancer to help them estimate their cancer risk.

Posted 9/27/16

Share your thoughts on this XRAYS article by taking our brief survey.
Article: New York Times report demonstrates need for genetic counseling, but doesn’t give the whole story

SUMMARY

A New York Times report discussed how genetic testing could provide “grim data” without guidance for patients. While this is a valid concern, this report does not sufficiently emphasize certain important issues regarding genetic testing, particularly the need for genetic counseling by a health care provider with expertise in genetics before and after genetic testing. (4/5/16)

STORY AT A GLANCE

A patient’s story about how genetic testing offered more confusion than answers was the topic of the New York Times (NYT) report, “When Gene Tests for Breast Cancer Reveal Grim Data but No Guidance.” This report discusses two types of genetic testing: germline testing that looks for
mutations in genes that increase cancer risk, and direct sequencing of tumor DNA to look for mutations in the tumor, which might help to optimize treatment.

The report begins with the story of a patient who had germline genetic testing, and was found to have a variation of unknown significance (VUS) in an unspecified gene, which led to confusion about the most appropriate treatment for her. The report then discusses how sequencing DNA from breast cancer tumors usually provides few answers for patients.

While these are valid concerns, this report raises many unaddressed issues. Nor were the ambiguous/troublesome cases in the report counterbalanced by stories of people who benefited from either germline or tumor genetic testing.

The Report Raised Concerns about Genetic Testing:

According to the report, the patient was about to begin radiation therapy after a lumpectomy for breast cancer. Her physician, a radiation oncologist, told her that, “A genetic test showed she had inherited an alteration in a gene needed to repair DNA. Radiation breaks DNA, so the treatment might actually spur the growth of her cancer.” The report also stated that the “surgeon urged her to not take the risk, and to have a double mastectomy instead.”

There is little research on how people with mutations in BRCA or other genes involved in repairing DNA respond to radiation treatment, nor are there national guidelines that recommend for or against radiation treatment in mutation carriers. A review of limited research published in 2015 says, “The present review also reassures that both BRCA1/2 mutation carriers are not proportionally more susceptible than non-carriers to radiation carcinogenic effects and radiotherapy of the first invasive breast cancer does not increase the risk of subsequent contralateral breast cancer.” Finally, while mutations in a few genes may inform a patient’s radiation therapy, it is critical to recognize that a variant of uncertain significance is not a worrisome finding. It is common, expected and should not change therapy. Patients who get a VUS on genetic testing should consult with a genetic counselor, medical geneticist, or other genetic specialist, since this is an area of great confusion to both non-genetics providers and patients.

“But patients need to be prepared for ambiguities [regarding genetic testing results]. “Typically they are not,” said an oncologist.

This example underscores the need for genetic counseling by a genetic counselor or medical geneticist before genetic testing. Patients who receive pre-test genetic counseling are made aware that while health care providers can interpret more genetic information than ever before, patients may still have ambiguous results that do not provide clear guidance for treatment or cancer risk management. A genetics
expert will discuss the possibility of an ambiguous result to help prepare the patient for that possibility, and then ask if the patient still wants to proceed with testing. Patients are not prepared for ambiguities when they do not see an appropriate health care provider, or when they see a health care provider who doesn’t thoroughly discuss the types of results patients may have, before they consent to genetic testing.

After the discussion with her radiation oncologist, the patient consulted with a medical geneticist, who told her that the mutation she had was not known to be harmful and recommended that she go ahead with the radiation therapy.

- Again, this case underscores how critical it is to have genetic counseling by a genetic counselor or medical geneticist. In addition to genetic counseling before genetic testing, patients should also see a genetic counselor or medical geneticist once the test results become known. This allows for a thorough discussion of what the results mean, how they fit with the patient’s personal and/or family history of cancer, and how they may affect the patient’s treatment and/or cancer risk management decisions. This case also emphasizes the need for better genetics education for frontline physicians who offer genetic testing to their patients.

The report notes that the patient carried a variation of unknown significance (VUS) in an unspecified gene. The report stated that, “Having a variation of unknown significance means it does not destroy the gene’s function, but may alter it—leaving the implications entirely uncertain.”

- This is an inaccurate explanation of what it means to have a variation of unknown significance in a gene associated with increased cancer risk. When a test result shows a VUS, it means that not enough information is available at the time to predict whether the change in the DNA sequence increases the patient’s cancer risk, or if it is not associated with the disease. The VUS may destroy the gene’s function, it may impair it slightly, or it may be harmless. Overall, most VUSs are entirely meaningless and do not impact healthcare. They should generally be ignored; nor should decisions about medical care be based upon a VUS. When a laboratory designates a test result as a VUS, it is acknowledging that a gene change is present, but more research is needed to determine if it is related to cancer development. Because of the inherent uncertainty surrounding VUSs, in this context, expert advice from a genetic counselor and/or medical geneticist is of exceptional importance.

Genetic testing does not offer clear-cut answers for everyone.

- Interpretation of a VUS is difficult for health care providers and patients, but with more people getting genetic testing, and increasing research on the function of specific types of VUS, researchers will be better able to determine whether or not those variations cause disease.
A number of ongoing international efforts are underway to establish extensive databases that will ultimately make more sense of VUSs.

“Yet now, as powerful new precision medicine() drugs elicit striking responses in patients with other cancers—lung, colon, melanoma, blood, gastric—metastatic() breast cancer patients have been left out.”

This statement implies that there are no precision drugs for metastatic breast cancer patients. While none were approved at the time of the article, clinical trials have been ongoing for PARP inhibitors, a type of targeted therapy() for men and women with both metastatic breast cancer and an inherited BRCA mutation. In addition, open clinical trials are looking at genetic changes in tumors from people with metastatic breast cancer. Such trials are the first step in bringing FDA-approved precision drugs to people with metastatic breast cancer.

This report switches between germline testing and breast cancer tumor gene testing without fully explaining the difference between the two

- Tumor testing looks for mutations that are only present in the tumor. Most of these mutations are not present in other cells because they develop as the cancer grows. This type of testing is different from the germline testing discussed at the beginning of the report.

- The NYT report concludes with a discussion about an oncologist who suggested that his patient have her tumor sequenced. The results, however, showed that none of the mutations found could be targeted with any drug. The physician is quoted as saying, “The results added nothing to her care.” While this particular patient may not have benefited from tumor sequencing, she had the potential to benefit from the process. Other oncologists have suggested tumor sequencing for their patients, and some of those patients have benefitted with targeted drugs. The NYT report gives a one-sided view of tumor sequencing. And while it is true now that most patients don’t benefit from tumor sequence analysis, this is an exciting area of research that many experts believe will one day be an important part of guiding cancer care for many patients.

- The report’s abrupt transition from germline testing to tumor testing may easily confuse readers who are unfamiliar with different types of testing, and give the impression that genetic testing does not change care decisions. It is important to remember that germline testing looks for mutations that are present at birth in every cell in the body, and can be passed on from mothers and fathers to sons and daughters. It is the type of genetic testing that shows whether or not a person is at increased risk for developing cancer, or that a patient’s cancer was likely due to an inherited mutation. People who carry mutations in genes that increase cancer risk are offered options to manage that risk, including increased screening and screening for other cancers associated with that gene mutation. Knowing that a person has an inherited mutation in BRCA or another gene that increases cancer risk can affect treatment
decisions, including type of surgery and chemotherapy, as well as opening up the possibility of participating in clinical trials that target cancers with BRCA mutations.

**Summary: “When Gene Tests for Breast Cancer Reveal Grim Data but No Guidance”**

Despite the shortcomings of this report, it does raise a valid concern: genetic testing can give patients and their health care providers access to lots of information about their inherited gene mutations and the genetic changes that occurred in their tumors. Not all of that information is associated with guidelines for care or treatment, however, and we still have much to learn about how to best interpret and use genetic information. Researchers have access to more genetic data than ever before, and it is a new and exciting time in the world of genetics! But in some cases, we are stepping into uncharted territory, and there will undoubtedly be ambiguities and unknowns. Researchers learn more every day to help healthcare providers provide clearer guidance to patients. Patients need to be told that sometimes genetic testing will give them results that are associated with guidelines for risk management and treatment, but there is a possibility that the test result will not provide clear answers.

Today, when a woman finds that she is a BRCA mutation carrier, she is put on a cancer screening regimen and is educated on all of her preventative care options. Expert guidelines identify how health care providers should care for BRCA mutation carriers—this wasn’t the case when BRCA was discovered in the early 1990s. That doesn’t mean that testing wasn’t worthwhile back then; it was just more confusing than it is today. Today we have care guidelines for Lynch Syndrome (Lynch Syndrome) patients, PTEN (PTEN) mutation carriers, TP53 (TP53) mutation carriers and others. Understanding how to care for all of these patients did not happen overnight.

Researchers and healthcare providers will undoubtedly understand more about these variations of unknown significance in the future, and additional treatments will be developed to target more tumor mutations. Today, patients should know that they may have ambiguous test results, and to consider whether or not they want to get genetic testing in the face of this possibility. But, the ambiguity is only one side of this story. Genetic testing regularly provides very important and helpful information to patients. While genetic testing may not always provide clear guidance, it often does, and that should not be downplayed. The bottom line is that it should be pursued in conjunction with experts who are familiar with the nuances of testing so that results can provide maximal benefit to patients.

Posted 4/5/16

Tell us what you think of this review by taking our brief survey

**References**
NCCN guidelines recommend genetic counseling and testing for people without cancer who have the following family history:

- A relative who has tested positive for an inherited mutation in a gene that increases cancer risk.
- One or more first- or second-degree relatives with breast cancer and any of the following:
  - diagnosed at age 45 or younger
  - triple-negative breast cancer
  - two separate breast cancers, with the first diagnosis at age 50 or younger
  - male breast cancer
- One or more first- or second-degree relatives with:
  - colorectal cancer before age 50
  - endometrial cancer before age 50
  - ovarian, fallopian tube, primary peritoneal cancer
  - rare or childhood cancers
- One or more first-degree relatives with:
  - metastatic or high-grade prostate cancer
  - pancreatic cancer
- Two or more relatives on the same side of the family diagnosed with any combination of the following at any age:


Other organizations have commented on this report as well:

Forman, A. and Daly MB. "Genetic Testing May Give Answers, But May Also Leave Questions." Fox Chase Cancer Center. Published on March 14, 2016.


Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
Study: Factors that affect the ability to work in people with metastatic cancer

SUMMARY

Some patients who live with metastatic cancer either want or need to continue working while coping with symptoms of their disease and treatment. A recent study that looked at over 600 people with metastatic breast, prostate, colon, or lung cancer found that about one-third of them continue working full or part time. People most likely to continue working were those undergoing hormonal treatment and those with less severe symptoms or side effects from treatment. (4/12/16)
Patients living with metastatic cancer often need or want to continue working. According to the study authors, “a better understanding of how metastatic cancer affects employment is a necessary step toward the development of tools for assisting survivors in this important realm.”

**Study findings:**

1. 35% (236 of 668) metastatic cancer patients were working full-time or part-time.
2. 45% (302 of 668) metastatic cancer patients stopped working because of their illness.
3. 20% (130 of 668) metastatic cancer patients were not employed for other reasons.
4. Factors that were associated with a higher likelihood of working were: receiving hormonal treatment (if that was an option), and minimizing symptoms such as fatigue, pain, and memory loss.

**Limitations:**

This was a retrospective study, meaning that the researchers retrieved all their data from previously documented records of past patients, rather than collecting patient data specifically for this particular study. Other factors that were not directly studied or known to these researchers may have affected employment in this setting. Additionally, the researchers acknowledged that the study may have attracted certain types of patients. For example, patients with metastatic cancer and severe symptoms may not have wanted to participate in the study about employment, and/or patients with relatively mild symptoms who were able to work full-time may not have visited the clinic as often where the study was recruiting participants, and missed the opportunity to participate. Importantly, this study only included people 65 years or older, so it is unknown if the same factors affect younger people diagnosed with metastatic cancers.

**What does this mean for me?**

This research indicates that some patients with metastatic cancer continue working; however, whether this is because they feel like they need to work or because they want to work is unknown. Researchers suggest that patients who need to or wish to continue working talk to their health care provider about how they can reduce the severity of their symptoms.

Posted 4/12/16

Share your thoughts on this XRAYS article by taking our brief survey.

**References**

ECOG-ACRIN cancer research group. “ECOG Performance Status.”

Disclosure

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

Questions to Ask Your Doctor

- I want to go back to work but I have symptoms from my treatment or my cancer. What options/treatments can improve my symptoms?
- What can I do to improve my symptoms enough so that I’m able to work more comfortably?
- I do not want to go back to work, but feel like I need to. How should I handle this?
- Do I qualify for disability benefits? Are there people who can help me apply?
The following resources focus on financial resources for people with, or at high risk for cancer.

- **FORCE resources**
  - Information: [Insurance and paying for care](#)
  - Information: [Health insurance appeals: Medicare and Medicaid](#)
  - Video: [Health Insurance and Your Legal Rights](#)
  - XRAY category: [Financial issues](#)
- **Triage Cancer**
- **Patient Advocate Foundation**
- **Cancer and Careers**
- **Lazarex Foundation** offers assistance to cover costs for travel and related expenses for clinical trials.

**WHO COVERED THIS STUDY?**

**MedicalXpress:**
Also published in:
This article can also be found on [News Medical](#)

**Study finds that more than one-third of patients with metastatic cancer continue to work** ★★★☆☆

**Cure Today**
**Getting back to work after a diagnosis of metastatic cancer** ★★★☆☆

**Medical Daily**
**Metastatic cancer negatively affects employment, but treating symptoms can help** ★★★☆☆

**Safety and Health**
**Symptom control may help metastatic cancer patients stay on the job: study** ★★★★☆

[How we rated the media](#)
IN DEPTH REVIEW OF RESEARCH

Study background:
Some metastatic cancer patients live for many years with their disease. As more people find themselves in this situation, they need to discuss employment and related topics with their health care provider. Cancer and cancer treatment affects employment, so these issues need to be addressed because “research suggests that cancer patients are more likely to return to work if information about managing problematic work activities is provided.” Unfortunately, very little information is available about patients living with metastatic disease.

Through the Symptom Outcomes and Practice Patterns (SOAPP) study, Amye Tevaarwerk and her colleagues from the University of Wisconsin-Madison and other institutions published an article in the February 2016 issue of Cancer that looked at how many metastatic cancer patients continue working, and what factors are associated with employment.

Researchers of this study wanted to know:
How metastatic cancer affects employment.

Population(s) looked at in the study:
This study included both male and female patients who:

- had breast, prostate, colon, or lung cancer.
- had metastatic disease.
- were 65 years old or younger.

Study findings:
1. 35% (236 of 668) of metastatic cancer patients were working full-time or part-time.
2. 45% (302 of 668) metastatic cancer patients stopped working because of their illness.
3. 20% (130 of 668) metastatic cancer patients were not employed for other reasons.
4. Factors that were associated with a higher likelihood of working were:
   - receiving hormonal treatment, if that was an option.
   - minimizing symptoms such as fatigue, pain, and memory loss.
   - being of non-Hispanic white ethnicity/race.
   - a better performance score on the ECOG (Eastern Cooperative Oncology Group) survey, which “describes a patient’s level of functioning in terms of their ability to care for themselves, daily activity, and physical ability.”
5. Factors that were NOT associated with the ability to continue working were:
   - disease type.
   - interval since metastatic diagnosis.
   - number of metastatic sites.
   - location of metastatic disease.
   - treatment status.

Limitations:
https://www.facingourrisk.org/XRAY/metastatic-breast-cancer-and-employment
This was a retrospective study, meaning that the researchers retrieved all their data from previously documented records of past patients, rather than collecting patient data specifically for this particular study. Other factors that were not directly studied or known to these researchers may have affected employment in this setting. Additionally, the researchers acknowledged that the study may have attracted certain types of patients. For example, patients with metastatic cancer and severe symptoms may not have wanted to participate in the study about employment, and/or patients with relatively mild symptoms who were able to work full-time may not have visited the clinic as often where the study was recruiting participants, and missed the opportunity to participate. Importantly, this study only included people 65 years or older, so it is unknown if the same factors affect younger people diagnosed with metastatic cancers.

Conclusions:

While more work needs to be done to understand employment for patients with metastatic disease, this study suggests that about one-third of people with metastatic cancer are currently employed either full-time or part-time. If continuing employment is something of interest, metastatic cancer survivors should discuss with their health care team what steps they can take to make their employment as comfortable as possible.

Posted 4/12/16

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SEARCH XRAY STUDIES AND ARTICLES

Keyword:  

Cancer Type:  

Choose

Relevant for:  

Choose Cancer Type First...

Categories:

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing

https://www.facingourrisk.org/XRAY/metastatic-breast-cancer-and-employment
Study: Is breast cancer risk increased in women who test negative for the BRCA mutation in their family?

SUMMARY

Some women who do not carry a BRCA mutation, but come from a BRCA-positive family, still develop breast cancer. This research examines whether these women are at higher risk for breast cancer, or whether their risk is similar to women in the general population. (4/19/16)

This article is relevant for:
- Women from a family with a known BRCA mutation who tested negative for the mutation in the family
- Women under 45
- Women over 45

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- Visit our XRAY blog

https://www.facingourrisk.org/XRAY/breast-cancer-risk-in-brca-negative-women
If women who test negative for the BRCA mutation in their families are at higher risk than women in the general population, they may require different screening or prevention.

**Study findings:**

1. Women who tested negative for their familial BRCA2 mutation were almost 5 times more likely to develop breast cancer than expected for an average-risk woman of the same age.

**Limitations:**

Women in this study who tested negative for BRCA may have been screened much more than women in the general population. Increased MRI or mammography could have resulted in more cancers being caught. Additionally, we have not identified and cannot always test for every gene that can affect cancer risk within families—abnormalities in other genes may influence risk in families with BRCA mutations. This study only looked at whether the women carried BRCA mutations; it did not consider whether they might have carried other genetic mutations that raise cancer risk. This is important, because if the BRCA-negative women who developed breast cancer carried mutations in other genes, their cancers could be attributed to those other mutations. Finally, this study was conducted through a cancer genetics clinic, a type of clinic that often sees families with very high cancer rates, which may have biased the results.

**What does this mean for me?**

More research needs to be done to understand if women who do not carry the BRCA mutation found in their family are still at higher risk of breast cancer than women in the general population. Even if you don’t test positive for your family’s mutation, having a first-degree relative who has had breast cancer raises your risk for developing the disease compared to women in the general population. Patients from high-risk families should speak with a genetics expert before and after genetic testing to understand their risk for cancer and determine a screening program that is appropriate for them.

Posted 4/19/16

**References**

Evans GR, Ingham SL, Buchan I, et al. “*Increased Rate of Phenocopies in All Age Groups in BRCA1/BRCA2 Mutation Kindred, but Increased Prospective Breast Cancer Risk Is Confinned to BRCA2 Mutation Carriers.*” Cancer Epidemiology, Biomarkers & Prevention. 2013 December; 22(12): 2269-2276.

The following organizations have resources related to genetic counseling and testing.

- FORCE related resources:
  - Information: [What is genetic testing?](#)
  - Information: [How to get genetic testing](#)
  - Information: [Hereditary cancer, genes and risk](#)
  - Personalized portal: [Genetic testing](#)
  - XRAY category: [Genetic testing](#)
  - Video: [ABC of Cancer Genetics](#)
  - Video playlist: [Genetic testing](#)
  - Blogs: [Genetic testing](#)

- [National Society of Genetic Counseling](#)
- [JScreen](#)

Updated: 12/05/2021

### WHO COVERED THIS STUDY?

**Medical News Today**

[BRCA-negative results may not reduce cancer risk](#) 🌟🌟🌟🌟🌟

**Huffington Post**

[Why women who test negative for BRCA mutation may still face a higher breast cancer risk](#) 🌟🌟🌟🌟🌟

**Fox News**

[Negative BRCA gene test doesn’t always mean lower breast cancer risk](#) 🌟🌟🌟🌟🌟

**EmaxHealth**

[Negative BRCA test not reliable for lower chance of breast cancer](#) 🌟🌟🌟🌟🌟

[How we rated the media](#)

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**IN DEPTH REVIEW OF RESEARCH**

Study background:
Researchers have noted the development of breast cancer in women who do not carry their family’s BRCA mutation. Researchers studied whether these women may have increased risk for breast cancer, even though they do not share their family’s BRCA abnormality.

In December 2013, Gareth Evans and his colleagues from the University of Manchester and other institutions published an article that examined whether women who tested negative for a familial BRCA mutation were at increased risk for breast cancer. Published over two years ago, the study raised a still controversial question regarding appropriate care for women who test negative for a BRCA mutation but are from a BRCA-positive family, as this is still an area of uncertainty.

Researchers of this study wanted to know:
Whether a woman with a negative BRCA test result may have increased risk of breast cancer if she is from a family that carries a BRCA mutation.

Population(s) looked at in the study:
This study included only first-degree relatives (parent or sibling) of BRCA mutation carriers in 809 families (428 BRCA1 families and 381 BRCA2 families).

Study findings:
1. Women who tested negative for their familial BRCA2 mutation developed breast cancer about 4.5 times more than expected for women of their age. Within this population, 14 breast cancers developed at the follow-up time, rather than the 3 that were expected.
   - This result was statistically significant, meaning that the result did not occur by chance, and was more likely to be a real finding.

2. Women who tested negative for their familial BRCA1 mutation developed breast cancer about 1.8 times more than expected for women of their age. Within this population, 7 breast cancers developed at the follow-up time, rather than the 4 that were expected.
   - This result was not statistically significant, meaning that it may have occurred by chance, and may not be a real finding.

Limitations:
Women in this study who tested negative for BRCA may have been screened much more than women in the general population. Increased MRI or mammography could have resulted in more cancers being caught. Additionally, we have not identified and cannot always test for every gene that can affect cancer risk within families with BRCA mutations. This study only looked at whether the women carried BRCA mutations; it did not consider whether they might have carried other genetic mutations that raise cancer risk. This is important, because if the BRCA-negative women who developed breast cancer carried mutations in other genes, their cancers could be attributed to those other mutations. Finally, this study was conducted through a cancer genetics clinic, a type of clinic that often sees families with very high cancer rates, which may have biased the results.

Conclusions:
The study authors wrote: “In the context of a family BRCA2 mutation, especially when there are multiple close relatives affected with early-onset breast cancer, specialists should advise that breast cancer risks may still be increased compared with the general population.” However, this is the result of only one study. Other work involving
this issue has resulted in the exact opposite conclusion: that a woman with a BRCA-negative test result for her family mutation is not at higher risk for breast cancer. Currently, the NCCN has no clear guidelines regarding care for women in this population, and more work is needed to understand the cancer risk for women who do not carry their familial BRCA mutation. This underscores the importance of genetic counseling by a genetics expert to determine what screening is appropriate for each individual woman.

**SEARCH XRAY STUDIES AND ARTICLES**

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**Categories:**

- Alternative Treatments
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- Clinical Trials
- Emotional Health
- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing
- Health Disparities
- Health Literacy
- Hereditary Cancer
- Intimacy & Body Image
- LGBTQIA+
- Male Breast Cancer
- Menopause
- Metastatic Cancer
- Nutrition & Exercise
- Palliative Care
- Pregnancy & Fertility
- Prevention
- Quality of Life
Study: Cellular diversity in tumors may predict survival for some types of breast cancer

SUMMARY

Some tumors are made up of many different types of cells, while others contain generally the same cell type. This study found that among people with high-grade breast cancer, those who have tumors made up of many different cell types have a lower 10-year survival rate than people with tumors containing only a single type of cells. This research is an early step towards developing a new test that can help physicians identify cancers that need more aggressive treatment, but more research is needed before it is ready for clinical use. (4/26/16)

This article is relevant for:

- People diagnosed with breast cancer that is “high-grade” or aggressive

This article is also relevant for:

- Breast cancer survivors
- ER/PR +
- Her2+ breast cancer
- Men with breast cancer

STUDY AT A GLANCE

This study is about:

Whether having many different types of cells (immune cells and connective tissue cells in addition to cancer cells, for example) within a breast cancer tumor affects a patient’s survival.

Why is this study important?

https://www.facingourrisk.org/XRAY/cellular-diversity-and-survival
Doctors want to be able to identify patients whose tumors need more aggressive treatment. If the presence of many different types of cells in a breast cancer tumor is a reliable marker for poor survival, this could be the basis of a test that would help doctors identify these patients.

**Study findings:**

1. Patients with high-grade breast cancer and tumors with many different types of cells had a 51% chance of surviving to 10 years.
2. Patients with high-grade breast cancer tumors without multiple cell types had a 70% chance of surviving 10 years.

**What does this mean for me?**

This research might become the basis of a test that predicts how aggressively a patient with high-grade breast cancer needs to be treated, based on the presence of multiple types of cells within the tumor. However, this is early research, and more work needs to be done before healthcare providers can use it in the clinic.

Posted 4/26/16

Share your thoughts on this XRAY review by taking our brief [survey](https://www.facingourrisk.org/XRAY/cellular-diversity-and-survival).

**References**


**Disclosure**

FORCE receives funding from [industry sponsors](https://www.facingourrisk.org/XRAY/cellular-diversity-and-survival), including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our [Scientific Advisory Board](https://www.facingourrisk.org/XRAY/cellular-diversity-and-survival) prior to publication to assure scientific integrity.

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**Questions to Ask Your Doctor**

- Is my cancer considered high-grade?
- I have an aggressive cancer—what are my treatment options?
- Are there any tests currently available that predict which breast cancer patients will benefit from chemotherapy?
WHO COVERED THIS STUDY?

Medical Daily
Having an ‘ecologically diverse’ tumor may affect breast cancer aggression ★★★★★☆☆

Fox News
Ecological imaging test may determine deadliness of breast cancer ★★★★☆☆☆

Medscape
‘Ecologically diverse’ breast cancer carries worse prognosis ★★★★★☆☆

University Herald
Scientists develop test to determine deadliness of breast cancer ★★★★★☆☆

How we rated the media

IN-DEPTH REVIEW OF RESEARCH

Study background:
Cancers differ from patient to patient. Some cancers grow quickly, while others evolve slowly. Some are more responsive to certain treatments. Physicians and researchers want to be able to identify cancers that are most dangerous and require the most aggressive treatment. Looking at cancer cells in different ways can help to predict their behavior. Researchers believe that the path a cancer takes depends on the two important characteristics: the cancer cells themselves, and how they interact with connective tissue (stromal) cells, immune cells, and other cells that surround and feed cancer cells. In this study, researchers looked at how the types of cells in and around the tumor, which they call the cancer’s ecosystem, can predict a patient’s chance of surviving their cancer.

In February 2016, Rachael Natrajan and colleagues at the Breast Cancer Now Toby Robins Research Centre at The Institute of Cancer Research in the United Kingdom and other institutions published a study in the journal PLOS Medicine exploring this topic. Their study looked at how having connective tissue cells and immune cells in addition to cancer cells within a tumor affected a patient’s survival.

Researchers of this study wanted to know:
If there is a connection between having different types of cells, including cancer cells, immune cells and connective tissue cells within a tumor, and 10-year survival of patients.

Population(s) looked at in the study:
This research study used 1,026 breast cancer tumors from women diagnosed between 1980 and 2005.

The researchers developed a program called the ecosystem diversity index (EDI) to determine which tumors had many different types of cells and which were composed of the same types of cells. A high EDI score (highest EDI=5) indicates that the tumor is extremely diverse (has many different types of cells); a low EDI score (lowest EDI=1)
indicates that the tumor is made up of the same type of cells.

**Study findings:**

1. Patients with high-grade breast cancer and a high EDI score (indicating tumors with multiple, different cell types) had a 51% chance of surviving to 10 years after diagnosis.

2. Patients with high-grade breast cancer and a low EDI score (indicating tumors made up of generally the same cell type) had a 70% chance of surviving 10 years after diagnosis.

3. A high EDI score did not predict survival for patients with low-grade breast cancer—having multiple cell types in the tumor did not decrease or increase the likelihood that a patient would survive their cancer.

4. Patients who had high-grade tumors, a high EDI, and a \( \text{TP53} \) mutation in the breast tumor DNA had an even lower (35%) chance of surviving to 10 years.

**Limitations:**

The researchers designed their program to look only at the three major cell types in breast tumors. These cell types could have been broken down into subtypes, which might have affected the results. Interestingly, researchers found that a high EDI score only affected survival for grade 3 breast cancer tumors. This could mean one of two things: as the research suggests, EDI scores can predict patient prognosis only among those with grade 3 tumors, or that tumor grading may slightly differ between pathologists, which may be a limitation of this study.

It is also important to note that this research used banked tumor samples that were matched to patients’ medical records. This is a critical first step in developing new tests, but more research in newly diagnosed breast cancer patients who have the benefit of current treatments must be done before this type of test can be developed for use in patients.

**Conclusions:**

Combined with genetic tumor testing, this study’s EDI scoring system may provide a future prognostic test. Further research must be done to confirm this finding, refine the test, and validate the results in patients before it can be used in the clinical setting.

While this test is in its early stages, prognostic tests, such as the Oncotype DX, which reliably identifies women with ER+ early-stage breast cancer who can be treated with hormone therapy alone, are already available; XRAYS reviewed recent research on this test last year.

**Posted 4/26/16**

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**SEARCH XRAY STUDIES AND ARTICLES**

Keyword:  

Cancer Type:

Choose

Relevant for:
Study: More patients with invasive breast cancer opting for double mastectomies

SUMMARY

Women diagnosed with invasive breast cancer have a number of surgical options. They can have breast-conserving surgery (lumpectomy) with radiation, a unilateral (single) mastectomy to remove only the tissue from the cancerous breast, or a contralateral prophylactic mastectomy (CPM), which removes both breasts. A new study finds that more women are opting for CPM, yet overall survival for these patients is not increasing. (5/3/2016)

STUDY AT A GLANCE

This study is about:

This article is relevant for:

- Women diagnosed with breast cancer who are recommended to undergo a single mastectomy

This article is also relevant for:

- Breast cancer survivors
- ER/PR +
- Her2+ breast cancer
Whether invasive breast cancer patients who elect to have contralateral prophylactic mastectomy (risk-reducing removal of a woman’s healthy breast when her opposite breast has breast cancer) have increased survival compared to women who have breast-conserving surgery (lumpectomy) with radiation or mastectomy only in the treated breast.

Why is this study important? Contralateral prophylactic mastectomy is an invasive surgical procedure that puts women at risk for complications such as infection. After diagnosis, some women are at high risk for a second breast cancer due to an inherited mutation in BRCA or another gene that increases breast cancer risk. However, according to the study authors, “the majority of women undergoing CPM are at low risk for developing a contralateral breast cancer.” Study authors reasoned that women who already have a low risk for a second breast cancer are unlikely to see a survival benefit by removing their healthy breast.

Study findings:
1. CPM among women with invasive breast cancer has increased significantly, from about 4% in 2002 to about 13% in 2012.
2. No significant improvement was found in breast cancer-specific survival or overall survival between women who had CPM compared to women who had breast-conserving surgery (lumpectomy) with radiation.

What does this mean for me?
Although CPM does not reduce the risk for dying of cancer, it does reduce the chance of a second breast cancer diagnosis, especially in high-risk women. This is particularly true for women with BRCA, other cancer-causing mutation, or a strong family history of cancer. In this study, researchers focused on survival, but women also choose CPM for other reasons. The decision on risk-reducing mastectomy is highly personal. Discuss all your options with your health care providers to decide which procedure is best for you.

Posted May 3, 2016

Share your thoughts on this XRAYS article by taking our brief survey.

References


Morrow M. “Prophylactic mastectomy of the contralateral breast.” Breast.
What is my risk of developing cancer in my other breast?

What complications may occur if I undergo contralateral prophylactic mastectomy?

I have invasive breast cancer; what are all of my options?

I have been diagnosed with breast cancer before age 45. Should I consider genetic testing before I make decisions about surgery?

I do not have a BRCA mutation, but I have a very strong family history of breast cancer. Should I consider contralateral prophylactic mastectomy?

I have a BRCA mutation, but I would like to avoid mastectomy. What are my risks for a second breast cancer?

WHO COVERED THIS STUDY?

CNN
Double mastectomies for breast cancer tripled in 10 years ★★★★☆

Medical Daily
Preventive double mastectomy rates have tripled in 10 years, and experts aren’t sure why ★★★★☆

Newsweek
More breast cancer patients choosing preventive mastectomy despite low rates of cancer recurrence ★ ★★★☆

TIME
The rate of double mastectomies has tripled in 10 years: study ★★★★☆

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Women with genetic mutations in BRCA and other genes associated with increased cancer risk, and women with a strong family history of breast or ovarian cancer benefit from contralateral prophylactic mastectomy (CPM) because they have a higher risk for a second breast cancer. However, these women represent less than one-third of women who choose CPM. Studies show that about 80%-98% of women who choose CPM do so because they want to prevent cancer in their other breast, yet the majority of women who choose CPM are at low risk of developing a second breast cancer.

In March 2016, Stephanie Wong and colleagues from the Harvard School of Public Health and other institutions published a study in Annals of Surgery that looked at the increasing rate of CPM, and assessed if it correlated to an improvement in survival.

Researchers of this study wanted to know:
Do increases in contralateral prophylactic mastectomy rates in women with invasive breast cancer result in longer survival for these patients?

Population(s) looked at in the study:
This study used data from the SEER (Surveillance, Epidemiology, and End Results) database, including 494,488 women who had stages 1, 2 or 3 unilateral breast cancer and were diagnosed between 1998 and 2012.

Study Findings:
1. The number of women with invasive breast cancer who chose contralateral prophylactic mastectomy (CPM) between 2002 and 2012 significantly increased, from about 4% in 2002 to about 13% in 2012.

2. The increase in breast reconstruction after CPM also increased, from about 35% in 2002 and to about 55% in 2012.

3. No significant improvement in estimated breast cancer-specific survival or overall survival was identified between women who had CPM compared to women who had breast-conservation (lumpectomy) with radiation.

4. Even when \( \text{HR} \) (hormone receptor) status (positive or negative) and age were factored in, the researchers still did not see any benefit in breast cancer-specific survival or overall survival.

**Limitations:**
This study used previously collected information from women through the SEER database—research using databases such as SEER is useful in designing controlled studies, which compare how different treatment options affect survival. Because the researchers did not collect the data themselves, they did not have all information about these women, such as their risk factors (genetic information, family history, other medical issues), socioeconomic status, or other potentially pertinent factors. The researchers also did not know the \( \text{HER2} \) receptor status of these patients (positive or negative), procedure preference of their surgeons, or what treatments these women had.

**Conclusions:**
This study suggests that in general, CPM provides no survival benefit in most women with invasive breast cancer. Additionally, a study done by Alison Kurian and colleagues from Stanford University and other institutions found similar results in Californian women, where “use of bilateral mastectomy increased significantly throughout California from 1998 through 2011, and was not associated with lower mortality than that achieved with breast-conserving surgery plus radiation.” However, they did find that women who underwent unilateral mastectomy had higher mortality than women who underwent bilateral mastectomy or breast-conserving surgery plus radiation.

It is important to remember that there are groups of women—carriers of BRCA or other mutations and women with a strong family history of breast cancer—who do see a survival benefit from CPM. Women have different reasons for choosing or not choosing CPM; survival is one reason but other reasons are equally valid. Ultimately, women should speak with their health care provider to make sure they understand the risks and benefits of CPM, and to determine what plan of action is most appropriate for them.

Posted May 3, 2016

Share your thoughts on this XRAYS article by taking our brief survey.

**Search XRAY Studies and Articles**

Keyword:  
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https://www.facingourrisk.org/XRAY/double-mastectomy-with-invasive-breast-cancer
Study: Financial burden affects quality of life of cancer survivors

SUMMARY

Cancer-related financial burden can keep survivors from getting the care that they need, yet how this burden affects mental and physical health is still unknown. A study found that almost one-third of cancer survivors report having financial burden; those most likely to be affected were under age 65, female, members of racial or ethnic minority groups, and people who lack access to adequate insurance. (5/17/16)

STUDY AT A GLANCE

This study is about:
How financial burden affects the quality of life of cancer survivors.

Why is this study important?
Financial burden from a cancer diagnosis and treatment can keep survivors from the medical care they need, resulting in delayed diagnosis, missed...
follow-up visits, and skipped treatments. But very little research has looked at how financial burden affects the physical and emotional health of cancer patients.

**Study findings:**

1. Among 19.6 million cancer survivors, about 29% report having cancer-related financial burden and indicating at least one of these problems:
   - outstanding loans or declared bankruptcy
   - worry about paying large medical bills
   - inability to cover cost of medical care visits
   - other financial sacrifices

2. Cancer survivors with financial burden were more likely to be depressed, worry about cancer recurrence, and scored lower on measures of physical quality of life.

**What does this mean for me?**

This study indicates that cancer survivors with financial burden are more likely to have a lower overall quality of life and reduced physical and mental/emotional health. According to the study authors, “Decreasing the financial burden of cancer is a complex problem that requires integrated efforts from health care systems, patients, and providers.” Patients who have financial trouble should discuss this with their health care providers.

Posted 5/17/16

Share your thoughts on this XRAYS article by taking [this brief survey](https://www.facingourrisk.org/XRAY/financial-burden-on-survivors).

**References**


The following resources focus on financial resources for people with, or at high risk for cancer.

- **FORCE resources**
  - Information: [Insurance and paying for care](#)
  - Information: [Health insurance appeals: Medicare and Medicaid](#)
  - Video: [Health Insurance and Your Legal Rights](#)
  - XRAY category: [Financial issues](#)

- **Triage Cancer**
- **Patient Advocate Foundation**
- **Cancer and Careers**
- **Lazarex Foundation** offers assistance to cover costs for travel and related expenses for clinical trials.

**Updated: 12/22/2021**

### WHO COVERED THIS STUDY?

**Wiley**
Also published in:
The same article was also covered by [Medical Xpress](#).

Many cancer survivors experience financial burdens that negatively affect their health and quality of life ★★★★★

**Medical News Today**
The financial burden of surviving cancer ★★★★★

**Healio**
Financial burden linked to depression in cancer survivors ★★★★★

**Oncology Nurse Advisor**
Cancer-related financial burden linked to lower quality of life ★★★★★

How we rated the media

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In-Depth (click to expand)
IN DEPTH REVIEW OF RESEARCH

Study background:
Multiple research groups have looked at how much patients spend related to cancer. One group observed that lost income and out-of-pocket care expenses cost breast cancer patients an average of $1,455 per month. Another group found that the average cancer patient had estimated out-of-pocket costs of about $4,727 per year. Previous studies have noted that 12% of all breast cancer patients are in debt four years after their diagnosis.

What remains unknown is how these financial problems affect the physical and mental health of cancer survivors. In March of 2016, Hrishikesh Kale and Norman Carroll from the Virginia Commonwealth University studied the quality of life of cancer survivors who were experiencing financial burden.

Researchers of this study wanted to know:
1. the scope of cancer-related financial burden.
2. whether there are predictors of who will experience financial burden due to cancer.
3. how financial burden affects the mental and physical health of cancer survivors.

Population(s) looked at in the study:
The study population represented 19.6 million cancer survivors through the 2011 Medical Expenditure Panel Survey (MEPS). The majority of this population was non-Hispanic white females who were diagnosed with cancer before age 65. This population included all cancers, but notably, 17% had breast cancer.

Study findings:
1. About 29% of 19.6 million cancer survivors report financial burden indicated by one or more of the following:
   - outstanding loans or declared bankruptcy
   - worry about paying large medical bills
   - inability to cover cost of medical care visits
   - other financial sacrifices

2. Cancer survivors who are most likely to experience cancer-related financial burden were:
   - diagnosed before age 65.
   - female.
   - had difficulty obtaining, or were without access to health insurance.
   - diagnosed with liver, lung, esophageal, or pancreatic cancers.
   - members of a racial/ethnic minority group.

3. Cancer survivors who had financial burden were more likely to:
   - be depressed, as measured by a patient health questionnaire.
   - worry about cancer recurrence (69% of survivors with financial burden were worried, compared to 35% of cancer survivors without financial burden).
   - score lower on measures of physical quality of life.

Limitations:
The Medical Expenditure Panel Survey data does not include information about the cancer stage, severity, or treatment used, so researchers could not control for these factors. Nor could they control for psychiatric illness that preceded a cancer diagnosis. This is a limitation, because if cancer survivors had a history of psychiatric illness before their diagnoses, the patient depression found in this study cannot be attributed to financial burden. Finally, because patients self-reported information through surveys, some information may have been incorrect (for example, exaggerations, omission of critical information, or simply forgetting details).

**Conclusions:**

This study suggests that cancer-related financial burden negatively affects the quality of survivors' mental and physical health. Cancer survivors who experience financial burden should ask for a referral to a social worker or patient navigator. These health care workers can connect patients to resources that provide financial assistance, access to low-cost medications, assistance with insurance appeals and support in navigating the health care and health insurance systems.

Posted 5/17/16

Share your thoughts on this XRAYS article by taking [this brief survey](https://www.facingourrisk.org/XRAY/financial-burden-on-survivors).

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- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing
- Health Disparities
- Health Literacy

https://www.facingourrisk.org/XRAY/financial-burden-on-survivors
Study: Do BRCA mutations affect fertility?

SUMMARY

Age affects fertility. As women age, their ovaries release eggs that are not as healthy as those released in younger women. Fewer eggs are released each menstrual cycle as women age, making it harder for older women to become pregnant. Are women with BRCA mutations less fertile? Previous research suggested that BRCA mutations might affect women’s fertility as she ages. A recent study found that BRCA1 mutation carriers may have slightly lower fertility than women without the same mutation, but more research is needed before this finding is useful for medical decision-making. (5/24/16)
Whether having a BRCA\(_1\) mutation affects ovarian reserve, which in general describes the capacity of ovaries to provide eggs that will ultimately result in a successful pregnancy.

**Why is this study important?**

"Ovarian reserve"—the amount of healthy eggs a woman has—is affected by her age. The older a woman gets the fewer healthy eggs she has to release from her ovaries each month. Because of this, age is often a factor in fertility and family planning. If having a BRCA mutation also affects fertility, this would be more important information for women to take into account for family planning.

**Study findings:**

1. BRCA\(_1\) mutation carriers had lower ovarian reserve, as measured by the concentration of the hormone AMH, than women who did not have BRCA1 mutations.
2. There was no difference in ovarian reserve between women with BRCA\(_2\) mutations and women without mutations in BRCA.

**What does this mean for me?**

While the association between BRCA1 mutation carriers and lower ovarian reserve adds to previous data, more research will need to be done to prove this link. The actual difference in ovarian reserve found in this study was relatively small. Women with BRCA mutations may want to consult with both genetics experts and fertility experts to coordinate their family planning and their plans for cancer screening and preventive surgeries. BRCA mutation carriers who have been diagnosed with cancer should request a referral to a fertility expert if they are concerned about the effects of treatment on their ability to conceive.

Posted 5/23/16

Share your thoughts on this XRAYS article by taking [this brief survey](https://www.facingourrisk.org/XRAY/brca-and-fertility).

**References**


Phillips K, Collins IM, Milne RL, et al. "[Anti-Mullerian hormone serum concentrations of women with germline BRCA1 or BRCA2 mutations](https://www.facingourrisk.org/XRAY/brca-and-fertility)." Human Reproduction. Published online first on April 19, 2016.


The following resources focus on fertility and cancer.

- FORCE fertility resources:
  - Information: [Fertility and Cancer Treatment](#)
  - Information: [Fertility and family planning](#)
  - Information: [Pregnancy after cancer](#)
  - XRAY category: [Fertility](#)
  - Video: [Fertility and Parenting Issues for Survivors and Previvors](#)
- [Alliance for Fertility Preservation](#) is an organization of healthcare professionals focused on fertility preservation.
- [SaveMyFertility.org](#) is a resource for cancer patients who want to learn more about preserving their fertility before and during cancer treatment, and protecting their hormonal health after treatment.

**Updated: 11/26/2021**

### WHO COVERED THIS STUDY?

**Medical News Today**

BRCA1 gene mutation linked to fewer eggs in ovaries ⭐⭐⭐⭐⭐

**Medical Daily**

BRCA1 mutations may negatively affect fertility: women with the gene have fewer eggs ⭐⭐⭐⭐

**Endocrinology Advisor**

BRCA1 mutation may affect fertility in women ⭐⭐⭐⭐

**Daily Mail**

"Angelina Jolie cancer gene" affects fertility: Women have fewer eggs and even IVF is less likely to work ⭐

See [How we rated the media](#)

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**IN DEPTH REVIEW OF RESEARCH**

**Study background:**

[https://www.facingourrisk.org/XRAY/brca-and-fertility](https://www.facingourrisk.org/XRAY/brca-and-fertility)
A woman is born with all of the eggs she will have throughout her life. Each month during her menstrual cycle, she releases one egg and in general, the healthier eggs are released when she is younger and the less healthy eggs are released later on. This is often referred to as lower ovarian reserve. Healthier eggs have a higher chance of resulting in a pregnancy, making it more difficult for women to get pregnant at older ages.

Some studies have suggested that BRCA genes are involved in reproductive aging, while others have not. Kelly-Anne Phillips and colleagues at the Peter MacCallum Cancer Centre in Australia and colleagues published findings in the journal Human Reproduction where they looked at how BRCA status affected ovarian reserve (as measured by concentration of the hormone called AMH (Anti-Müllerian hormone) in the blood.

**Researchers of this study wanted to know:**

1. Does having a BRCA1 or BRCA2 mutation result in women having a lower ovarian reserve?

**Population(s) looked at in the study:**
The researchers used blood samples from 172 BRCA1 mutation carriers and 216 women from families with BRCA1 mutations who did not carry the mutation in their family, as well as 147 BRCA2 mutation carriers and 158 women from families with BRCA1 mutations who did not carry the mutation in their family. These women were between the ages of 25-45, had two intact ovaries and had no personal history of any cancer (except for non-melanoma skin cancer). Researchers measured AMH (Anti-Müllerian hormone) concentrations in the blood, which is a measurement of ovarian reserve as AMH is a hormone produced by eggs and represents a woman’s overall egg pool. AMH is a good measurement of ovarian reserve and is one of the most important tests that fertility specialists use when counseling patients.

**Study findings:**

1. On average, BRCA1 mutation carriers had lower ovarian reserve as measured by AMH concentrations than women who did not carry BRCA1 mutations.
   - The difference is comparable to a two-year increase, meaning a 35-year old woman who is a BRCA1 carrier and a 37-year old woman who is a non-carrier had similar ovarian reserves.

2. There was no difference between the average ovarian reserve as measured by AMH concentrations between women with BRCA2 mutations and women without BRCA2 mutations.

**Limitations:**
The sample size used in this research study was relatively small. While the researchers saw that there was no difference in AMH concentrations between BRCA2 carriers and non-carriers, this may be because there were not enough BRCA2 patients in the study for the researchers to see a difference.

**Conclusions:**
While this study suggests an association between BRCA1 mutation status and a lower ovarian reserve, more work needs to be done to confirm this finding, in addition to the BRCA2 finding, as it was a relatively small study. Additionally, because the difference in AMH concentrations between BRCA1 mutation carriers and non-carriers was not large, the authors write "...it is possible that the findings of our study might not translate to clinically relevant fertility implications for younger women, but may be important for the subgroup of BRCA1 mutation carriers who wish to conceive in their late 30s or 40s when fertility is reduced even in the general population." Young BRCA1 mutation carriers do not need to rush to have children based on these findings alone. However, women in their late 30s and 40s do already have a reduced ovarian reserve due to age—may want to talk to a fertility expert, particularly if they are having trouble conceiving. These experts may suggest trying to conceive at an earlier age or freezing their eggs.
Study: Can long periods of fasting protect against breast cancer recurrence?

**SUMMARY**

Previous research in mice suggested that long periods of fasting provide protection against factors that are associated with a poor cancer outcome. A new study associates prolonged fasting (13 hours or more) at night with a lower risk of breast cancer recurrence, but no association between fasting time at night and mortality. While these findings are interesting, more research needs to be done to confirm them. In the meantime, breast cancer survivors should discuss any concerns about nutrition with their health care providers. 05/30/16
How nighttime fasting affects breast cancer recurrence and mortality.

Why is this study important?
If longer fasting at night is linked to a better breast cancer prognosis, as the study authors write, “Prolonging the length of the nightly fasting interval may be a simple non-pharmacologic strategy for reducing the risk of breast cancer recurrence.”

Study findings:
1. Women who reported fasting fewer than 13 hours per night had an increased risk of breast cancer recurrence compared to women who reported fasting for more than 13 hours per night.

What does this mean for me?
Everyone has a period of nighttime fasting—from their last meal or late night snack until breakfast. This study looked at the length of that interval, and suggests that late night eating, which shortens the length of the nighttime fast, is associated with breast cancer recurrence. But this study does not definitively conclude that nighttime eating results in breast cancer recurrence; only that there is an association. A large, controlled trial with patients who are randomly assigned to either the nighttime fasting group or a control group is needed to provide more definitive information and confirm this association. Additionally, no current research indicates that late night eating is associated with worse health outcomes. Based on the results of this study, lengthy nighttime fasting is not needed to prevent cancer recurrence.

Research on weight gain and late night eating has produced mixed results—researchers still do not know whether late night eating makes it easier to gain weight. However, dieticians recommend avoiding late night eating because they say it is easy to overdo eating at nighttime (eating out of boredom or stress instead of hunger, for example, and portions are not as well controlled). Ultimately, the results of this research should not stop women from eating a light snack at night when hungry.

Posted 5/31/16

Share your thoughts on this XRAYS article by taking this brief survey.

References

Disclosure
FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific.
WHO COVERED THIS STUDY?

Medical Daily
Night Fasting: not eating for 13 hours or more every night may reduce risk of breast cancer recurrence ★★★☆☆

The Telegraph
Simple night-time trick could stop breast cancer returning ★★★★★☆☆

Medical News Today
Nightly fasting may help reduce breast cancer risk ★★★★★☆☆

The Washington Post
Why breast cancer survivors should avoid late-night eating ★★★★★☆☆

Daily Mail
Avoid late night snacks to prevent breast cancer returning: Women who fast for over 13 hours slash their risk by a THIRD ★★★★★☆☆

How we rated the media

IN-DEPTH REVIEW OF RESEARCH

Study background:
Previous work in mice that were fed a high-fat diet showed that long periods (16 hours) of fasting protected the mice from inflammation and weight gain, two factors that are associated with a poor cancer outcome. However, nothing is currently known about how long periods of fasting affect human breast cancer recurrence and mortality. Catherine Marinac and her colleagues from the University of California, San Diego and other institutions published a report in the journal JAMA Oncology looking at whether the length of time a person goes without eating at night could predict recurrence and mortality for women with early-stage (stages I-III) breast cancer.

Researchers of this study wanted to know:
Does fasting at night help prevent breast cancer recurrence and mortality?

Population(s) looked at in the study:
This research used data from 2,413 women who participated in the Women's Healthy Eating and Living (WHEL) study. These women had early-stage breast cancer (stages I-III), did not have diabetes, and were between the ages of 27-70 years old. Their dietary assessment consisted of multiple phone calls in a three-week period when they were
asked what they ate and when they ate. The women were questioned in the year they enrolled in the study (baseline), the next year, and then again two years later. All 2,413 women completed the baseline assessment, about 91% completed the assessment the next year, and about 80% completed the assessment the last year.

**Study findings:**

1. Women who reported fasting for fewer than 13 hours per night had a 36% increased breast cancer recurrence risk compared to women who reported fasting for more than 13 hours per night. This increase is modest.

2. No association was found between fasting time at night and mortality due to breast cancer.

**Limitations:**

This study used data taken from the Women’s Healthy Eating and Living (WHEL) study; researchers did not produce the questions asked from the dietary assessment, or control for other things they might have wanted to ask. Additionally, the women were asked to self-report their diets and times that they ate. Self-reporting is a definite study limitation, because, memory is not infallible—women may forget the exact time they ate—and is subject to many biases. The study also followed women for a four-year period, so whether this effect lasts over longer periods is unknown. Finally, it is unclear whether shorter nighttime fast periods are responsible for the increase in recurrence or if other lifestyle factors that accompany shorter nighttime fasting, such as alcohol consumption, amount of sleep a person gets each night, or other lifestyle choices that leads to the increase in recurrence risk play a role.

**Conclusions:**

While this study suggests that long periods of fasting at night are associated with protection against breast cancer recurrence, more work needs to be done to confirm this finding. A large clinical trial would also allow researchers to control for other factors, such as when the women sleep. Many previous studies have found an association in people who sleep at times that disrupt their natural circadian rhythm and an increased risk for breast cancer. Based on this study, women do not necessarily need to avoid eating a light snack at night if they are hungry.

Posted 5/31/16

Share your thoughts on this XRAYS article by taking [this brief survey.](https://www.facingourrisk.org/XRAY/fasting-and-recurrence)

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Categories:

- [ ] AND
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- Alternative Treatments

https://www.facingourrisk.org/XRAY/fasting-and-recurrence
Study: Dense breast notifications are informative but hard to read and understand

SUMMARY

Some states offer women dense breast notifications that are meant to explain that dense breasts are risk factors for breast cancer and can hide cancer on mammograms, and to identify appropriate supplemental screening options. But recent research found that this information is often not easy to read or understand, which questions the usefulness of the documents. (6/7/16)
Information that is difficult to read or understand may fail its purpose to inform women about dense breasts, whether they may have them, and important alternatives to mammograms.

**Study findings:**

1. The majority of DBNs explain that breasts with dense tissue can hide cancer on mammograms, and that they are linked to an increased risk of breast cancer. The notifications also identify other options for screening dense breasts. But while these DBNs include all of this information, researchers found that the documents are hard to understand, and the majority of them were written at a reading level that is too high.

**What does this mean for me?**

This research indicates that dense breast notifications, while informative, are difficult to read and understand. Women who have any questions about their DBN or screening results should never hesitate to contact their health care provider for clarification, because it is important that all patients understand information that is presented to them.

Posted 6/7/16

Share your thoughts on this XRAYS article by taking [this brief survey](https://www.facingourrisk.org/XRAY/dense-breast-notification).

**References**


**Disclosure**

FORCE receives funding from [industry sponsors](https://www.facingourrisk.org/XRAY/dense-breast-notification), including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our [Scientific Advisory Board](https://www.facingourrisk.org/XRAY/dense-breast-notification) prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

The New York Times
Notifications about dense breasts can be hard to interpret

Boston University
Also published in:
The same article was also covered by Medical Xpress

Healio
Studies address appropriate ways to notify, screen women with dense breasts

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Dense breasts can hide cancer on mammograms, and they are a risk factor for cancer. Because of this, almost half of U.S. states include information on dense breasts with mammogram results, because it can help women make informed decisions about what to do next.

Nancy Kressin and her colleagues from the Boston University School of Medicine published a letter in the journal JAMA regarding their efforts to determine whether information included in DBNs is readable and understandable.

Population(s) looked at in the study:
The researchers studied the dense breast notifications from all states that issue them. They assessed content, readability (using two tests that measure the reading grade level of text) and understandability (using the Patient Education Materials Assessment Tool that measures patient understanding).

Study findings:
1. 24 of 50 U.S. states require that women’s screening results also include a dense breast notification. The researchers studied the DBNs of 23 of these states.
   - 7 of 23 states require that all women receive generic information about breast density. Women with dense breasts get additional information on breast density.
   - 16 of 23 states provide information about breast density only to women who have dense breasts.

2. All of the 23 states included in the study provide dense breast notifications that mention the potential for dense breasts to hide cancers on mammograms.

3. 18 of 23 states provide dense breast notifications that include information about the increased risk of breast
cancer that is linked to dense breasts.

4. 14 of 23 states provide dense breast notifications that include information about supplemental screening for women with dense breasts.

5. On average, DBNs reviewed are written at a 10th grade reading level. This is higher than the recommended reading level (7th-8th grade) for patient information.

6. All dense breast notifications reviewed have very low understandability scores.

**Limitations:**

While this study focused on the text included in dense breast notifications, it did not have any data on related outcomes. Did the women from states with dense breast notifications have less anxiety or more cancer detected? So while the researchers know about the readability and understandability of dense breast notifications, they do not know how these factors affect women after they receive their mammogram results. Further research is needed to determine whether the current low reading level of dense breast notifications improve a patient’s ability to make decisions about breast cancer screening.

**Conclusions:**

This study indicates that the reading level of dense breast notifications is too high, making them hard to understand. Another study is needed to see the effect this has on outcomes, but as the study authors wrote, “Efforts should focus on enhancing the understandability of dense breast notifications so that all women are clearly and accurately informed about their density status, its effect on their breast cancer risk and the harms and benefits of supplemental screening.” If dense breast notifications are hard to read and understand, women may glance over and disregard the information, even though it is information that they should know about themselves. If a patient is having difficulty understanding her dense breast notification or any screening result, she should not hesitate to contact a health care provider for further clarification.

It is important to remember that dense breasts are just one indication for increased breast cancer screening. Women with a family history of cancer, a mutation in BRCA1/2 or other gene that increases breast cancer risk, or a personal history of breast cancer should discuss appropriate breast cancer screening with their health care providers.

Posted 6/7/16

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**SEARCH XRAY STUDIES AND ARTICLES**

Keyword: 

Cancer Type: 

Choose

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Choose Cancer Type First...
Study: Does light alcohol consumption affect your breast cancer risk?

SUMMARY

Alcohol is known to increase breast cancer risk, but does that include light consumption? This study indicates that some breast cancer occurrences and mortality is due to light alcohol consumption. (06/21/16)

This article is relevant for:

- Women who drink alcohol and are concerned about their breast cancer risk.

This article is also relevant for:

- Women under 45
- Women over 45
- Healthy people with average cancer risk

STUDY AT A GLANCE

This study is about:

Understanding how breast cancer occurrence and mortality relate to drinking alcohol, focusing on “light” drinking.

Why is this study important?

https://www.facingourrisk.org/XRAY/light-alcohol-and-breast-cancer
Breast cancer has many causes, most of which cannot be controlled. Drinking alcohol is a risk factor for breast cancer, people can use that information to decide if they want to change their alcohol consumption as a lifestyle modification to lower their breast cancer risk.

**Study findings:**

1. About 9% (144,000) of global breast cancer cases result from alcohol consumption.
   - About 19% of this group consists of women who were considered “light” drinkers (less than two drinks per day).

2. About 7% (38,000) of global breast cancer deaths result from alcohol consumption.
   - About 18% of this group consists of women who were considered “light” drinkers (less than two drinks per day).

**What does this mean for me?**

Many studies have pointed to alcohol consumption as a risk factor for breast cancer. This study suggests that “light” drinking can contribute to breast cancer occurrences and deaths. While the study authors define “light” drinking as less than two drinks per day, the U.S. government’s Dietary Guidelines for Americans suggests that women consume one drink per day at most. Women should try to follow these guidelines. It is important to keep in mind that consuming one drink will not cause cancer.

Posted 06/21/16

Share your thoughts on this XRAY review by taking our brief [survey](https://www.facingourrisk.org/XRAY/light-alcohol-and-breast-cancer).

**References**


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

Clare County Review
New study links light alcohol consumption to increased risk of breast cancer ★★★☆☆☆

Medical News Today
Breast cancer risk rises even with light alcohol use ★★★☆☆☆

The Drinks Business
New study links 'light drinking' to increased risk of breast cancer ★★★☆☆☆

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Alcohol is a carcinogen (something that is capable of causing cancer), and the International Agency for Research on Cancer has confirmed a relationship between alcohol and breast cancer. However, because the link between "light" alcohol consumption and breast cancer is still controversial, Kevin D. Shield and his colleagues from the Section of Cancer Surveillance published research in Alcoholism: Clinical and Experimental Research in June 2016 to better understand this relationship.

Researchers of this study wanted to know:
Is "light" drinking a contributor to breast cancer occurrence and mortality?

Population(s) looked at in the study:
The study researchers pooled data together from two databases: GLOBOCAN 2012 for the estimated number of breast cancer cases by age, sex, and country; and the Global Information System on Alcohol and Health for alcohol consumption information. Researchers then developed a model that combined the information from both databases to model the alcohol consumption for the population. They used a method called Population-Attributable Fraction to determine the amount of breast cancer cases and mortality that were due to alcohol consumption.

Study findings:
1. About 9% (144,000) of global breast cancer cases result from alcohol consumption.
   - About 61% of this group is 60 years old or younger.
   - About 19% of this group consists of women who were considered “light” drinkers (less than two drinks per day).
   - Breast cancer cases were most common in Northern and Western Europe.
2. About 7% (38,000) of global breast cancer deaths result from alcohol consumption.
- About 50% of this group is 60 years old or younger.
- About 18% of this group consists of women who were considered “light” drinkers (less than two drinks per day).
- Breast cancer mortality was most common in Central and Eastern Europe.

**Limitations:**
Because researchers used secondary data—they didn’t collect it themselves—they weren’t able to ask questions about alcohol consumption, or control for other issues or factors that they might have wanted to know. Additionally, they were unable to assess how “light” drinking affected women who are already at higher risk of breast cancer (due to BRCA1 mutations, for example). And while the researchers were able to look at the percentage of breast cancer incidence and mortality for patients 60 years old and younger and patients older than 60 years, they did not break up the age groups further (for example, 40-49, 50-59, etc.). Finally, their computer modeling does not take into account the cancer burdens between different populations, such as people from a lower socioeconomic group (where research has shown an increased breast cancer mortality) or between different ethnic groups.

**Conclusions:**
This study suggests that “light” drinking does result in breast cancer occurrence and mortality for some people. While this study relied on previously collected data and estimates from a computer program to develop these results, considerable prior research has established the link between alcohol consumption and breast cancer. The Dietary Guidelines for Americans suggests women drink no more than one alcoholic drink per day. Women should try to follow this recommendation, and to keep in mind that consuming one drink will not cause cancer. Cancer is complicated and caused by multiple factors, many of which cannot be controlled.

06/21/16

**SEARCH XRAY STUDIES AND ARTICLES**

**Keyword:**

**Cancer Type:**

Choose

**Relevant for:**

Choose Cancer Type First... 

**Categories:**

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk

https://www.facingourrisk.org/XRAY/light-alcohol-and-breast-cancer
Study: Breast cancer risk model updated for average risk women with genetic, lifestyle and environmental information

SUMMARY

A number of factors are known to increase breast cancer risk, but some of these factors have not been included in models to predict breast cancer risk. This study looks at an updated model that includes some of these factors, such as genetics, smoking, and drinking. The goal of the model is to give women a more individualized breast cancer risk assessment. (6/29/16)
Research on breast cancer risk factors that can be incorporated into a model to predict a Caucasian woman's breast cancer risk.

Why is this study important?

Research has identified lifestyle and environmental factors such as alcohol consumption, smoking, menstrual and/or reproductive history, hormone use, height, and weight that can increase breast cancer risk. We now also know about common changes in DNA called "single nucleotide polymorphisms" (SNPs) that can also increase breast cancer risk. SNPs are different from mutations in BRCA or other genes found on hereditary cancer panels, as they have been shown to only slightly modify cancer risk. Researchers want to incorporate this information into a breast cancer risk prediction model to identify those women who are at higher risk of developing breast cancer.

Study findings:

1. On average, 30-year old white women in the U.S. have about an 11% risk for developing invasive breast cancer by age 80. However, according to the model the researchers developed, breast cancer risk can range from about 4% for some women to about 24% for other women.

What does this mean for me?

The researchers of this study developed a model that takes into account information updates about factors that increase breast cancer risk. This information can be used to predict which women have a slightly higher or slightly lower risk of breast cancer. Some risk factors are known as "nonmodifiable," meaning that their influence on breast cancer risk cannot be changed or is unlikely to be changed. Genetics, family history, and some components of menstrual and or reproductive history are examples of nonmodifiable risk factors. However, the researchers observed that if women with the greatest increase in risk from nonmodifiable factors had low body mass index (BMI), did not drink or smoke, or use hormone therapy, they could still, at age 80, have comparable breast cancer risk as women who did not have an increased risk due to nonmodifiable risk factors.

Although lifestyle changes can help to lower your breast cancer risk, this particular risk prediction model has not been validated for clinical use, meaning health care providers are not currently using it to counsel women on their breast cancer risk. The study authors state that "randomized trials will be needed to understand the true effect of an intervention for the underlying population..." in other words, they do not know with certainty that altering modifiable lifestyle factors will prevent breast cancer. Women should talk to their health care provider to determine what individual measures they should take to reduce their breast cancer risk.

Posted 6/29/16

Share your thoughts on this XRAYS article by taking our brief survey.
New breast cancer risk model updated to include genetics, lifestyle and environmental factors

The American Cancer Society (ACS) guidelines on exercise, nutrition and weight for cancer prevention recommend the following:

### Diet and nutrition

- Follow a healthy eating pattern, which includes:
  - foods that are high in nutrients in amounts that help you get to and stay at a healthy body weight.
  - a variety of vegetables, fiber-rich legumes (beans and peas), and whole fruits in a variety of colors. ACS recommends people consume at least 2½ to 3 cups of vegetables and 1½ to 2 cups of fruit each day, depending on your calorie requirements.
  - whole grains rather than refined grains. ACS recommends that at least ½ of your grain consumption consists of whole grains.
- A healthy eating pattern limits or does not include:
  - red and processed meats.
  - sugar-sweetened beverages.
  - highly processed foods and refined grain products.
- It is best not to drink alcohol. People who do choose to drink alcohol should:
  - have no more than 1 drink per day for women or 2 drinks per day for men.

### Exercise

- Exercise regularly.
  - Adults should get at least 150 minutes of moderate-intensity activity (equal to a brisk walk) or 75 minutes of vigorous activity (makes your heartbeat and breathing faster and makes you sweat) each week, preferably spread throughout the week.
  - Physical activity has been shown to lower the risk of several types of cancer, including breast, endometrial, prostate[1] and colon cancer. It also reduces the risk of other serious diseases such as diabetes and heart disease.

### Weight

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References


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https://www.facingourrisk.org/XRAY/breast-cancer-risk-model
WHO COVERED THIS STUDY?

Cancer Therapy Advisor
Model predicts that healthful lifestyle benefits women at risk of breast cancer ★★★★★☆☆☆☆☆

Fox News
Key lifestyle factors could help reduce breast cancer cases by 30 percent ★★★★★☆☆☆☆☆

Oncology Nurse Advisor
Healthy lifestyle could reduce risk of developing breast cancer ★★★★★☆☆☆☆☆

TIME
Here are the things women can do to avoid breast cancer ★★★★★☆☆☆☆☆

NBC News
Even people with breast cancer risk genes can lower risk ★★★★★☆☆☆☆☆

Collective Evolution
These lifestyle choices lower your breast cancer risk, even if you’re genetically predisposed to it ★★★★★☆☆☆☆☆

Pulse Headlines
28.9% of all breast cancers can be prevented by controlling 4 risk factors ★★★★★☆☆☆☆☆

How we rated the media

IN-DEPTH REVIEW OF RESEARCH

Study background:
Some breast cancer risk-increasing factors can be changed—for example, a woman can choose not to smoke. Others are known as “nonmodifiable,” meaning that their ability to alter breast cancer risk cannot be changed or is unlikely to be changed. Genetic factors, such as an individual’s DNA, are a good example of nonmodifiable risk. Researchers do not know how information about nonmodifiable risk factors, such as single nucleotide polymorphisms (SNPs), common DNA changes found in the general population; family history; and some components of menstrual and or reproductive history can guide cancer prevention efforts with modifiable risk factors (such as drinking, smoking, and weight).
Paige Maas and her colleagues from the National Cancer Institute and other institutions published research in the journal *JAMA Oncology* describing their breast cancer risk model that incorporates both modifiable and nonmodifiable risk factors to predict a woman’s 80-year breast cancer risk.

**Researchers of this study wanted to know:**

Can risk factors such as single nucleotide polymorphism (SNPs) and other lifestyle/environmental factors be incorporated into a breast cancer risk prediction model?

**Population(s) looked at in the study:**

This study used information from women participating in the Breast and Prostate Cancer Cohort Consortium. Researchers used information from 17,171 White women with invasive breast cancer, and 19,862 white women without invasive breast cancer (controls) to develop a breast cancer risk model for all white women in the U.S. The information included data on 24 single nucleotide polymorphisms (SNPs) that are known to increase breast cancer risk, and that the researchers included in their model. While SNPs are a DNA alteration, they are commonly found in the general population, and do not increase cancer risk as much as a known cancer-causing gene mutation—92 common SNPs are believed to increase breast cancer risk. For SNPs not included in the Breast and Prostate Cancer Cohort Consortium, the researchers used previously published data in their model. This population did not include women with mutations in BRCA1; it did include women with specific SNPs in *BRCA2* and *CHEK2*, but not all known mutations.

**Study findings:**

1. On average, 30-year old white women in the U.S. have about an 11% risk for developing invasive breast cancer by age 80. However, according to the model the researchers developed, breast cancer risk can range from about 4% for some women to about 24% for other women.

2. Women with the greatest increased risk due to nonmodifiable risk factors who did not smoke, drink, or use menopausal hormone therapy, and had a low BMI could have a decreased risk at age 80, similar to an average woman who was not at increased risk due to the same nonmodifiable risk factors.

3. The researchers estimate that about 29% of all breast cancer cases in the U.S. could be prevented if all white women refrained from drinking, smoking, or using hormone therapy, and had a healthy BMI.

**Limitations:**

The researchers defined nonmodifiable risks as those that could not be changed or were unlikely to be changed in regard to their ability to alter breast cancer risk. However, some of the factors they considered nonmodifiable do have components that can be changed. For example, height, the age at onset of menstruation, and the age at onset of menopause are partially determined by body size, childhood diet, and exercise habits. Additionally, because the researchers did not evaluate all breast cancer risk factors—they did not collect data directly from these women—they were unable to ask about education level, breastfeeding, physical activity, breast conditions (mammographic density and benign breast disease), and hormone biomarkers (estradiol, testosterone, and prolactin). Nor did they look at genetic mutations, such as BRCA mutations, that cause disease; they looked only at single nucleotide polymorphisms. And because not all the data was available from one single study, the researchers had to combine data from multiple studies, increasing the inconsistencies in the overall data used in this study. Finally, the researchers did not include data on women with many known mutations in cancer risk-increasing genes which, depending on the gene mutation, can increase cancer risk substantially.

**Conclusions:**
This study suggests that maintaining healthy lifestyle choices regarding smoking, drinking, menopausal hormone therapy use, and BMI can help to prevent breast cancer, even in women whose high risk for breast cancer is due to genetics and family history. More work, including a large clinical trial, needs to be done to confirm these findings and to see if altering these lifestyle factors results in fewer breast cancer cases. Models need to be developed for races other than Caucasian. Future studies should also include other factors that increase breast cancer risk, including genetic mutations (while the highest lifetime risk in this study was 24%, the lifetime risk for a woman with a \textit{BRCA} mutation is as high as 65%). Because of the multiple sources of data used by the researchers, \textit{William Dupont and colleagues wrote in an accompanying editorial, “Since [the model] cannot be calibrated, we would not recommend that it be used to counsel individual patients.”} While the authors of the editorial praise the progress achieved of the research study, they state that it would be premature to use the model to support clinical decision making. Women should talk to their health care providers to identify lifestyle changes that they can incorporate into their lives to help lower their breast cancer risk. Adopting a healthy lifestyle is important for many aspects of health in addition to lowering cancer risk.

Posted 6/29/16

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- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing
- Health Disparities
- Health Literacy

https://www.facingourrisk.org/XRAY/breast-cancer-risk-model
Study: Breastfeeding may reduce hormone receptor negative breast cancer risk

SUMMARY

Previous studies have shown that women who breastfeed have a reduced breast cancer risk. This study examines this association in the different breast cancer subtypes (ER, PR, HER2 negative/positive) and finds that breastfeeding is associated with a reduced risk of ER-/PR- breast cancer. (11/16/2015)

This article is relevant for:
- Women who are pregnant or have just given birth and are deciding about breastfeeding
- Previvors
- Women under 45
- Healthy people with average cancer risk

Be part of XRAY:

https://www.facingourrisk.org/XRAY/breastfeeding-and-breast-cancer-risk
Any action that can lower the risk for breast cancer—the most common cancer in women—has significant impact. Scientists are particularly interested in finding ways to reduce the risk for triple-negative breast cancer because it is aggressive and it has a poorer prognosis.

**Study findings:**

Breastfeeding was associated with a risk reduction of about 20% for triple-negative breast cancer, and a 10% reduction in risk of HER2+.  

1. breast cancers that were also ER-/PR-.

**What does this mean for me?**

After looking at results from many pooled studies, data shows that women who breastfeed have lower rates of two types of aggressive breast cancers: triple-negative breast cancer and ER/PR-negative/HER2-positive breast cancer. While the research suggests a link, scientists cannot state for certain that breastfeeding lowers the risk for these breast cancers. Nevertheless, for women who are pregnant, planning a pregnancy or have just given birth, this study adds an additional reason to consider breastfeeding.

Posted 11/16/15

Share your thoughts on this XRAY article by taking our brief survey.

**References**


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

Oncology Nurse Advisor
Breastfeeding may reduce risk of hormone receptor-negative breast cancers ★★★★★☆☆

The Jewish Voice
Reduced risk of breast cancer linked to breast feeding: study ★★★★★☆☆

Youth Health
Breastfeeding can help women reduce their risk of developing aggressive breast cancer ★★★★★☆☆

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Previous studies suggested a relationship between breastfeeding and breast cancer: longer length of breastfeeding is linked with lower rates of breast cancer. Not all breast cancers are the same. Breast cancers can be categorized into different types based on the presence or absence of various markers, specifically estrogen receptor (ER), progesterone receptor (PR), and/or HER2, another cell marker. If none of these markers are present, the cancer is considered to be “triple negative.” Many past studies on breastfeeding and breast cancer did not take into account the presence or absence of HER2. In this paper, Dr. Marissa Weiss of Breastcancer.org and colleagues at the American Cancer Society, Washington University School of Medicine, and Icahn School of Medicine at Mount Sinai were interested in how this relationship may differ between different cancer types.

Researchers of this study wanted to know:
The association between breastfeeding and risk of specific types of breast cancer.

Population(s) looked at in the study:
Researcher looked 27 previous studies published through 2014. The studies used information from 36,881 human breast cancer cases, and provided information about the association between breastfeeding and type of breast cancer.

Study findings:
Breastfeeding was associated with:

1. a risk reduction of about 20% for triple-negative breast cancers.
2. a risk reduction of about 10% for HER2 positive cancers that were also ER and PR negative.

Breastfeeding did not greatly affect the risk of ER and PR positive breast cancers, regardless of HER2 status.
Limitations:

The association between breastfeeding and triple-negative breast cancer risk should be confirmed with further research, because only a small subset of the studies looked at triple-negative breast cancer. The results from this study complement the findings of a previous study, which also found that breastfeeding reduced breast cancer risk in BRCA1 carriers (who are more likely to develop triple-negative breast cancers). However, other studies have not shown that breastfeeding reduces cancer risk.

This report is a meta-analysis (a paper that uses data from previous studies). Meta-analyses have certain inherent weaknesses. One pitfall is that the analysis is only as strong as the studies included. Another is that the different study designs of the research included in the analysis may affect the overall analysis.

This study also did not take into account several factors, including the BRCA mutation status, income, race, ethnicity, or access to high quality medical care of the participants; these omissions may also have affected the meta-analysis results. Experts warn that given these limitations, more research is needed before we know with certainty whether or not breastfeeding reduces breast cancer risk, and if so, in what kind of breast cancer, and which women are most likely to benefit. Women who cannot breastfeed or who chose not to breastfeed should not be concerned, as other lifestyle choices have been shown to reduce breast cancer risk.

Conclusions:

The association between breastfeeding and breast cancers that are hormone receptor-negative, both ER/PR-negative and HER2-positive, or triple-negative, is interesting. While this analysis did not find a strong association between breastfeeding and ER and/or PR-positive breast cancers, some studies included in this meta-analysis found a protective association between hormone receptor-positive breast cancer risk and breastfeeding when results were analyzed individually. More work needs to be done to look at this relationship, and to further study how breastfeeding may be conferring a reduced risk of hormone receptor-negative breast cancers.

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- Alternative Treatments
- Basic Science
- Cancer Diagnosis

https://www.facingourrisk.org/XRAY/breastfeeding-and-breast-cancer-risk
Study: Aerobic exercise lowers estrogen levels in premenopausal women at high risk for breast cancer

SUMMARY

Many treatments that lower estrogen levels also reduce breast cancer risk. Unfortunately, these treatments are also associated with negative side effects. A recent study looked at the effect of regular aerobic exercise on the estrogen levels of women who are at high risk for breast cancer. (11/14/2015)
Removing the ovaries and taking risk-reducing medications such as tamoxifen have been shown to reduce breast cancer risk; however, both are associated with short-term and long-term side effects. Aerobic exercise does not have negative long-term consequences, and is an accessible activity for people, so understanding if exercise can also lower estrogen levels is the first step in determining whether or not it can be used to reduce breast cancer risk in young women who are at high risk for breast cancer.

Study findings:

1. Premenopausal women at high risk for breast cancer who participated in regular aerobic exercise for 5 months had lower estrogen levels than women who did not exercise regularly.

What does this mean for me?

This study looked only at the effect of exercise on estrogen levels in premenopausal women at high risk for breast cancer—it did not directly measure the effect on breast cancer risk. Researchers found that exercise was associated with lower estrogen levels, which may reduce breast cancer risk. This is most likely to be relevant only in women whose cancer cells use estrogen receptors (ER), allowing estrogen to spur the growth of ER-positive breast cancer. Many high-risk women, including those with BRCA1 mutations, develop triple-negative breast cancer, which does not utilize the estrogen receptor; this suggests estrogen levels might not be as relevant for these women.

Regardless of its effect on breast cancer risk, exercise is extremely beneficial for many aspects of health: it helps to control weight; prevent heart disease, diabetes and high blood pressure; boosts energy; and improves mood and sleep. Everyone is encouraged to talk with their health care providers about how they can make exercise part of their routine. Women at high risk for breast cancer should continue to maintain a heightened breast cancer screening schedule with their health care provider even when engaging in an exercise program.

Posted 11/14/15

Share your thoughts on this XRAYS article by taking our brief survey.

References


The American Cancer Society (ACS) guidelines on exercise, nutrition and weight for cancer prevention recommend the following:

Diet and nutrition

- Follow a healthy eating pattern, which includes:
  - foods that are high in nutrients in amounts that help you get to and stay at a healthy body weight.
  - a variety of vegetables, fiber-rich legumes (beans and peas), and whole fruits in a variety of colors. ACS recommends people consume at least 2½ to 3 cups of vegetables and 1½ to 2 cups of fruit each day, depending on your calorie requirements.
  - whole grains rather than refined grains. ACS recommends that at least ½ of your grain consumption consists of whole grains.
- A healthy eating pattern limits or does not include:
  - red and processed meats.
  - sugar-sweetened beverages.
  - highly processed foods and refined grain products.
- It is best not to drink alcohol. People who do choose to drink alcohol should:
  - have no more than 1 drink per day for women or 2 drinks per day for men.

Exercise

- Exercise regularly.
  - Adults should get at least 150 minutes of moderate-intensity activity (equal to a brisk walk) or 75 minutes of vigorous activity (makes your heartbeat and breathing faster and makes you sweat) each week, preferably spread throughout the week.
  - Physical activity has been shown to lower the risk of several types of cancer, including breast, endometrial, prostate (1) and colon cancer. It also reduces the risk of other serious diseases such as diabetes and heart disease.

Weight

- Get to and stay at a healthy weight.
  - Being overweight or obese is a risk factor for many cancers, including
IN DEPTH REVIEW OF RESEARCH

Study background:
Some types of cancer need the hormone estrogen to grow. Because of this, many breast cancer treatments and risk management strategies focus on reducing estrogen levels. Past studies have shown that BRCA mutation carriers who reported exercising during adolescence had lower breast cancer risk or a delayed breast cancer diagnosis, suggesting that there might be a relationship between exercise and breast cancer risk. Dr. Kathryn Schmidt and colleagues at University of Pennsylvania investigated whether or not exercise could affect estrogen levels in women at high risk for breast cancer. Rather than ask women how often they exercised, this study measured women’s estrogen levels before they began an exercise program, and again 5 months after they participated in a monitored aerobic exercise program.

Researchers of this study wanted to know:
How exercise affects estrogen levels in premenopausal women at high risk for breast cancer.

Population(s) looked at in the study:
The study included 135 women, who at the start of the study:

- had never had breast cancer.
- had a BRCA mutation OR a first-degree relative (mother, father, sibling) with a BRCA mutation.
- classified as high risk based on one of two models used to predict breast cancer risk
- were between ages 18-50 and not in menopause.
- participated in aerobic exercise no more than 75 minutes per week for six months prior to beginning the study.
Women were followed over 7 menstrual cycles, with the first 2 months used to establish their normal estrogen levels, and the final 5 months used to monitor changes in their estrogen levels when they participated in a prescribed aerobic exercise regimen. Women were placed into one of three groups:

- One group continued their normal pattern of less than 75 minutes of aerobic exercise per week.
- One group was assigned to a low level of aerobic exercise of 150 minutes per week.
- One group worked up to a high level of aerobic exercise of 300 minutes per week.

**Study findings:**

Hormone levels naturally change during different phases of the menstrual cycle. When researchers followed the women’s hormone levels at different stages of their menstrual cycle, they found that:

- every 100 minutes of exercise reduced estrogen levels by about 4% at the first day of menstrual bleeding (the follicular phase).
- exercise did not affect estrogen levels after ovulation (the luteal phase).
- exercise did not affect levels of progesterone, another hormone that can drive breast cancer growth in either phase.
- For every 100 minutes of exercise, women showed a decrease of approximately 10% in a type of dense breast tissue called “fibroglandular tissue.” Previous studies have shown that increases in the amount of fibroglandular tissue correlate to increased breast cancer risk.

**Limitations:**

This was a relatively small study of women who were all at high risk for breast cancer. Further studies would be needed to compare the results in young women with average breast cancer risk. The study followed women for 5 months, so whether the reduction in estrogen levels seen would be maintained is unknown.

In addition, the short study period could only follow reduction in estrogen levels; women would need to be followed for a longer time to show that this reduction in estrogen levels is directly associated with a lower breast cancer risk. This was the most crucial limitation of the study—investigators looked at estrogen levels, yet changes in estrogen levels may not result in any change in breast cancer risk.

**Conclusions:**

The results of this study show that exercise reduces estrogen levels, meaning that it might perhaps reduce risk of breast cancer, particularly in women who have the estrogen receptor (ER+). While the study was small, exercise is beneficial for many aspects of health other than cancer, and that is why all everyone is encouraged to discuss the best way to incorporate exercise into their regular routines.

While a reduction in estrogen might reduce the risk of breast cancer developing, it is not yet a certainty. Patients should talk with their health care providers about all the methods they should be using to reduce their risk of developing cancer. In this study, exercise did not lower estrogen levels as much as removing ovaries or taking medications such as tamoxifen or raloxifene. Additionally, medications have been tested in randomized clinical trials and demonstrated to reduce breast cancer risk, whereas exercise has not. Women at high risk for breast cancer are encouraged to discuss national guidelines that outline risk management for people at high risk for breast cancer with their health care providers and maintain a regular schedule of breast cancer screening.

Posted 11/14/15
Study: Do antioxidants encourage the spread of cancer cells?

SUMMARY

Scientists do not yet know why some cancers spread to other parts of the body (a process called metastasis). A study in mice suggested that high doses of some antioxidants (chemicals that can protect cells from damage) might actually make it easier for cancer cells to spread. (12/01/2015)

This article is relevant for:

- The clinical relevance of this study for people is not clear

This article is also relevant for:

- Men with breast cancer
- Triple negative breast cancer
- ER/PR +
- Her2+ breast cancer

https://www.facingourrisk.org/XRAY/antioxidants-and-cancer-spread
Learning what causes cancer cells to spread can help scientists design better ways to stop this process. Antioxidants include some vitamins and nutrients that can be found in foods or taken as supplements. They protect our cells from some of the damage that occurs from day-to-day life; for example, exposure to the environment, sun, hormones, etc. Research has looked at whether taking antioxidant supplements can prevent cancer in people, and results have been mixed. In some studies, taking large amounts of certain antioxidant supplements has led to poorer outcomes among patients.

**Study findings:**
The study found that very large doses of antioxidants promoted spread of melanoma cells in mice.

**What does this mean for me?**
People often wonder if eating certain foods or taking supplements can help them prevent or treat their cancer. Research on the relationship between antioxidant supplements and cancer is complicated and has produced mixed results. Results vary by the population studied, the type of cancer, the antioxidant used, and even the dose. Studies in people have shown that increasing dietary antioxidants does not reduce cancer risk. In some research studies vitamin E supplements have been linked to an increase in the chance of being diagnosed with or dying from prostate and lung cancers.

The doses of antioxidants used in this study are much higher than what people would normally get from their diet. According to experts, eating a healthy diet should provide most people with enough of the antioxidants needed for good health. You should speak with your doctor before taking any antioxidant dietary supplements.

Posted 12/1/15

**References**

**Final Recommendation Statement**
Vitamin Supplementation to Prevent Cancer and CVD: Counseling, February 2014.

**Disclosure**
FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

**Newsweek**

Antioxidants may lead to cancer spread, study says ★★★ ★★

**Washington Post**

The latest study about antioxidants is terrifying. Scientists think they may boost cancer cells to spread faster ★

**RT**

Antioxidants are good for you …until you get cancer and they feed the disease ★★★ ★★★

How we rated the media

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**IN DEPTH REVIEW OF RESEARCH**

**Study background:**

Cells undergo a process called metastasis to spread from a primary tumor to other sites in the body. Few cancer cells can survive the metastasis process to spread and grow at another site in the body. It is not fully understood how cells that manage to metastasize are able to do so. Dr. Sean Morrison and colleagues at the University of Texas Southwestern Medical Center looked at the capability of metastasized melanoma cells to withstand oxidative stress. (Oxidative stress, which can damage cells, occurs when an imbalance develops between reactive oxygen species (ROS) and the body’s ability to remove them.) ROS occurs naturally in the body as oxygen is processed; they are damaging, but our bodies usually have a sufficiently strong system response to handle it. ROS increase during times of environmental stress, such as exposure to ultraviolet (UV) light or ionizing radiation. Molecules called antioxidants play a role in controlling ROS. Antioxidants are produced by the body and are also found in many different foods. Some antioxidants are sold as over-the-counter dietary supplements.

**Researchers of this study wanted to know:**

How oxidative stress and antioxidants affect the ability of melanoma cells to metastasize.

**Population(s) looked at in the study:**

Cancer cells from four patients with non-metastatic melanoma and four patients with metastasized melanoma were injected into mice that lacked functioning immune systems.

**Study findings:**

1. Changes in melanoma cells in the blood and at distant points from the primary tumor indicated oxidative stress that was not found in the rodent’s primary tumors.

2. Melanoma cells that successfully metastasized withstood oxidative stress.

3. Large doses of the antioxidant N-acetyl cysteine (NAC) promoted metastasis.

https://www.facingourrisk.org/XRAY/antioxidants-and-cancer-spread
Limitations:
This study was done in mice that did not have functioning immune systems, allowing researchers to inject and study human tumor cells in a mouse model. Though the researchers used melanoma cells from human patients samples, observing what happens when they were transplanted into immunodeficient mice does not exactly correlate to what happens in human cancer patients with functional immune systems. In addition, the number of different patient samples used in this study was relatively low, which means that there is a possibility that the results the researchers see are unique to those tumors. Researchers did note that melanoma metastasis in the study mice is predictive of clinical outcomes—in other words, the cancer cells that metastasized in human patients also metastasized in the mice. While this may be true, it does not mean that the mechanism that the cells use to metastasize is exactly the same in the two species, or that a functional immune system may affect the process.

Conclusions:
Not too long ago, the idea that antioxidants are beneficial was well received, and clinical trials looked at giving cancer patients supplementary antioxidants. Recently, however, this idea is being questioned. This study indicates that oxidative stress limits the ability of melanoma cells to metastasize; when researchers added antioxidants to relieve oxidative stress, more metastasis occurred. The antioxidant treatments used in these mouse studies may help us understand how cancer acts, but the path from antioxidant treatments in genetically altered mice to clinical application is a long one, and not all study results in mice hold true in human patients. More work needs to be done to fully understand this process and how it might impact cancer patients.

However, the data from previous clinical trials prompted the U.S. Preventive Services Task Force (USPSTF) to recommend against the use of Vitamin E and Beta-carotene (antioxidants) for the prevention of cardiovascular disease or cancer. The USPSTF also says that there is not enough data to recommend for or against the use of multivitamins (which include antioxidants) for the prevention of cardiovascular disease or cancer.

It is also important to note that the antioxidants injected into mice in this study were pure, supplemental treatment antioxidants. They included much greater antioxidant levels than what a person would get from a normal, healthy diet. In the context of this study, a greater dose of treatment antioxidants promoted metastasis. People with cancer, and those who have a high risk of cancer, should continue to eat a healthy diet that includes a variety of fruits and vegetables.

posted 12/01/15

View All

SEARCH XRAY STUDIES AND ARTICLES

Keyword:

Cancer Type:

Choose

Relevant for:

Choose Cancer Type First...
Study: Effects of cancer diagnosis and treatment during pregnancy on the health and development of the child

SUMMARY

Very little work has studied how a woman's cancer diagnosis and treatment during pregnancy affects her child. This study of women who were diagnosed with cancer while pregnant looks at their children at ages 18 months and 3 years. The study found no difference in general, cognitive, and cardiac development when compared to children born to healthy mothers. (12/08/2015)
Mothers who are diagnosed with cancer during a pregnancy may have many questions, such as:

- Will the cancer affect my baby?
- Will the chemotherapy and/or radiation treatments I receive affect my baby?
- Should I delay treatment until my baby is born?
- Should I consider terminating my pregnancy?

These are all important questions because external factors like drugs, alcohol, and smoking are known to affect fetal development.

This study takes a general look at how cancer during pregnancy affects the health and development of the children during early childhood.

**Study findings:**

1. No differences in cognitive, cardiac, or general development were found between 3-year old children of mothers who were diagnosed with cancer while pregnant with them, and 3-year old children of mothers without cancer.

**What does this mean for me?**

While the results of this study are positive and promising, more work needs to be done to fully understand the effect of cancer diagnosis and treatment on a developing fetus. These results only look at children up to age 3, so long-term follow-up from this study will be important to understand whether prenatal exposure to maternal cancer and treatments may affect children as they grow.

Posted 12/08/15

**References**


Greene, MF and Longo, DL. "Cautious Optimism for Offspring of Women with Cancer During Pregnancy." New England Journal of Medicine, Vol 373, No. 19, pp. 1875-76, November 5, 2015. (must have a subscription to access)

**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

New York Times

Study offers support for cancer treatment during pregnancy

Study finds chemo and radiotherapy are not unsafe

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Research on how cancer diagnosis in a pregnant woman and any subsequent chemotherapy and/or radiation therapy affect the fetus and its development after birth has been limited. Dr. Frédéric Amant of the University Hospitals, Leuven, Belgium and colleagues from the International Network on Cancer, Infertility, and Pregnancy collaborated on this multicenter international study of children born to mothers who were diagnosed with cancer during their pregnancy. The study was published in The New England Journal of Medicine in November.

Researchers of this study wanted to know:
Are there developmental effects in babies born to mothers who were diagnosed with cancer during their pregnancy?

Population(s) looked at in the study:
The researchers compared 129 children born to mothers diagnosed with cancer during their pregnancy to 129 children of mothers who did not have cancer while pregnant. The children from mothers without cancer were the same gestational age (born at the same number of weeks) as the children born to mothers diagnosed with cancer. Mothers with all types of cancers were included in this study, but notably more than half the women in the study had breast cancer during pregnancy.

The mothers in the study who had cancer had the following treatments:

- 13 had surgery
- 41 had chemotherapy
- 1 had radiation therapy
- 48 had surgery and chemotherapy
- 3 had surgery and radiation therapy

https://www.facingourrisk.org/XRAY/effect-of-diagnosis-during-pregnancy
3 had chemotherapy and radiation therapy
4 had surgery, chemotherapy, and radiotherapy
1 had Herceptin, a targeted therapy, for HER2+ breast cancer
1 had Interferon β, an immune therapy
14 had no treatment while pregnant

**Study findings:**

1. About 61% of the children whose mothers were diagnosed with cancer while pregnant were born before their due date. However, most were less than 2 weeks early, meaning the babies were close to full term.

2. Medical issues and surgical needs were similar between the children whose mothers were diagnosed with cancer and those who were not.

3. No overall difference was found in cognitive development at 18 months or 3 years between the children of mothers diagnosed with cancer and the children with mothers who did not have cancer.
   - Researchers also looked at children of mothers who had chemotherapy while pregnant; they also found no differences in cognitive development between them and the children of mothers who did not have cancer.

4. Three-year-olds whose mothers were diagnosed with cancer while pregnant with them had no differences in heart rate, blood pressure, or other indicators of heart health when compared with three year olds of mothers who did not have cancer while pregnant.

**Limitations:**

While promising, this study has several limitations.

- The authors note that age 3 may be too soon to see heart, cognitive, or other problems that may develop in the future.
- These results may not apply equally to all chemotherapy treatments—researchers did not look at separate chemotherapy treatments; rather, they combined all types of chemotherapy treatments into one analysis.
- Few women in the study received radiation, so it is difficult to make conclusions about this form of treatment.
- Because women were treated at different points of their pregnancy, conclusions cannot be drawn about the timing of treatment during pregnancy.
- The study did not include newer "targeted" therapies, so no conclusions can be made about these types of treatments.

Because the prenatal exposure group contained children who were born to mothers with very different treatments (including those who had no treatment), it was not possible to determine whether the cancer itself or the cancer treatment affects the developing child.

**Conclusions:**

The researchers were quoted in some reports saying that they plan to expand this study to add more participants, and follow them until age 18 to see what effects prenatal exposure to cancer may cause as they grow older. This is an important follow-up because this current study is relatively small and has no data on children older than 3 years.
In an editorial in the *New England Journal of Medicine* that accompanied the article, Drs. Michael Greene and Dan Longo of the Department of Obstetrics and Gynecology at the Massachusetts General Hospital suggested that it is still prudent to avoid cancer treatment in the first trimester of pregnancy. More work needs to be done to understand individual contributions of the cancer itself or different treatments that might affect a developing fetus to help women who are diagnosed during pregnancy make informed decisions.

Posted 12/08/15

**SEARCH XRAY STUDIES AND ARTICLES**

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**Categories:**

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing
- Health Disparities
- Health Literacy
- Hereditary Cancer
- Intimacy & Body Image
- LGBTQIA+
- Male Breast Cancer
- Menopause
- Metastatic Cancer
- Nutrition & Exercise
- Palliative Care
- Pregnancy & Fertility
Study: How many children with cancer have mutations in genes that increase cancer risk?

SUMMARY

Many genes are associated with increased cancer risk in adults, but it is unclear how common these mutations are in children with cancer. This study found that about 9% of children with cancer carry mutations in a gene that is known to increase cancer risk. Over half of the mutations were in the TP53 gene, which is associated with increased cancer risk at a young age and increased risk of breast cancer in adults. (12/15/2015)

Contents

- At a glance
- Findings
- Questions for your doctor

STUDY AT A GLANCE

This study is about:

How often mutations in genes associated with inherited cancer risk occur in children with cancer.

Why is this study important?
Knowing if a child’s cancer is caused by an inherited gene mutation that is associated with increased cancer risk may help doctors and scientists understand the growth of their cancer, expand options to care for the patient, and assure access to genetic counseling for the children’s families.

**Study findings:**

1. About 9% of pediatric cancer patients had an inherited mutation in a gene associated with increased cancer risk.
2. 40% of children with mutations in genes associated with increased cancer risk had a known family history of cancer.
3. Most commonly, mutations found were in the TP53 gene, which is associated with increased risk of numerous cancers in children and adults, including breast cancer.

**What does this mean for me?**

Mutations in genes associated with increased cancer risk in adults are also found in children with cancer. If pediatric cancer occurs in your family, you may want to talk to your doctor about genetic testing.

Posted 12/15/15

**References**


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

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**Questions to Ask Your Doctor**

- As the parent of a child with cancer, should we consider genetic testing?
- I have a mutation in TP53; what type of screening should my family consider?
- I carry a mutation in a gene that increases my risk of cancer; what does this mean for my child?
- I’m an adult survivor of childhood cancer, should I have genetic testing?
WHO COVERED THIS STUDY?

**NBC News**

Gene scan finds surprising mutations in kids with cancer ★★★★★

**Scientific American**

Childhood cancer risk hides in families ★★★★★

**TIME**

Doctors find 'crystal ball for childhood cancer' in gene study ★★★☆☆☆

**Huffington Post**

Many children with cancer were born with genes that increase risk ★★★★★

How we rated the media

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**IN DEPTH REVIEW OF RESEARCH**

**Study background:**
While numerous studies have examined the role of inherited mutations that cause adult cancer syndromes, less research has been conducted regarding inherited pediatric cancers. Some pediatric cancers are known to be inherited, yet the genetic basis of many is still unknown. In a paper published in the *New England Journal of Medicine*, Dr. James Downey and colleagues at the St. Jude Children’s Research Hospital sequenced over 500 different genes, including 65 genes associated with increased cancer risk, in patients who developed cancer before age 20.

**Researchers of this study wanted to know:**
How many children with cancer have inherited mutations in a gene that increases cancer risk.

**Population(s) looked at in the study:**
Researchers tested blood samples from 1,120 cancer patients under 20 years old who had various cancers, including:

- leukemia (52.5%)
- brain and spinal cord cancers (21.9%)
- neuroblastoma (8.9%)
- bone cancers, including osteosarcoma (3.5%) and Ewing’s sarcoma (4.1%)

Researchers also looked at genetic test results from people without cancer to determine how common mutations in these genes are in the general population. The samples came from:

- the 1,000 Genomes Project, a project that provides an overview of human genetic variation
Study findings:

1. About 9% of the pediatric cancer patients had mutations in genes that are already known to increase cancer risk; this is about 9 times higher than what was found in people from the 1,000 Genomes Project (about 1%) and the National Database for Autism Research population (also about 1%).

2. The most commonly mutated gene—found in 50 of the 95 pediatric cancer patients with mutations—was TP53. Mutations in this gene cause Li-Fraumeni syndrome, which predisposes people to developing many different types of cancers (including breast, brain and soft tissue cancers), often at a young age.

3. Other gene mutations associated with increased cancer risk that were found in the pediatric patients included:
   - APC, associated with familial adenomatous polyposis, which is characterized by increased colon cancer risk (6 patients).
   - BRCA2 (), associated with hereditary breast and ovarian cancer (6 patients).
   - PMS2 (), associated with Lynch syndrome (), which is characterized by increased risk of numerous cancers, including colon, ovarian, stomach, and brain (4 patients).

4. 8 children had mutations in BRCA1 (), BRCA2 (6), and PALB2 () (1), which are associated with adult-onset cancers, including breast cancer. These children had leukemia, central nervous system tumors, neuroblastoma, osteosarcoma, and rhabdomyosarcoma. However, the percentage of children with these mutations was not significantly different from the percentage that has been found in the average population without cancer.

5. An additional 20% of children had a variant of uncertain significance () (VUS) in one of the genes tested, meaning researchers are unsure if the mutation is associated with increased cancer risk.

6. Only 40% of the patients with these gene mutations and an available family history actually had a family history of cancer in their close blood relatives (parents, siblings, grandparents, aunts, or uncles).

Limitations:

This study did not consider whether or not parents or relatives of the pediatric cancer patients were also mutation carriers; researchers would not be able to tell if some mutations were new or were associated with a cancer risk within the family.

While the researchers found mutations that are known to increased cancer risk, the study did not directly show that the children’s cancers were caused by these mutations. This is particularly important in the case of gene mutations associated with adult-onset cancers, such as BRCA1, BRCA2, and PALB2.

Conclusions:

About 9% of the 1,120 pediatric cancer patients had a mutation in a gene associated with increased cancer risk. This may reflect an underestimate, as the mutations included are already associated with a hereditary cancer syndrome (such as TP53 for Li-Fraumini syndrome, and BRCA () for breast and ovarian cancer) and did not include other genes.

The fact that only 40% of the patients with mutations had a family history indicates that other factors should be involved in determining the need for genetic testing in children with cancer.
It is interesting that 8 of the children had mutations in the BRCA1, BRCA2, or PALB2 genes, which are known predispose adults to cancer. However, this study did not show that the mutations directly led to the cancer in these children. It is important to note that pediatric cancers are still quite rare, and only a very small percentage of patients in this study had mutations in BRCA or PALB2. The results establish no reason to think that mutations in BRCA1, BRCA2, or PALB2 increase risk of pediatric cancers.

Abnormalities in TP53, a gene that is already known to increase the risk of pediatric cancer, was the most commonly identified mutation in this study. National guidelines for management of people with mutations in TP53 include notifying pediatricians about increased risk of childhood cancers. Also, parents of children in families with known mutations in TP53 are currently offered the option to have their children undergo genetic testing.

SEARCH XRAY STUDIES AND ARTICLES

Keyword:

Cancer Type:

Choose

Relevant for:

Choose Cancer Type First...

Categories: AND - OR

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing
- Health Disparities
- Health Literacy
- Hereditary Cancer
- Intimacy & Body Image
- LGBTQIA+
- Male Breast Cancer
- Menopause
- Metastatic Cancer

https://www.facingourrisk.org/XRAY/childhood-cancer-and-mutations
Study: Study uses mice and brains from deceased Alzheimer’s patients to assess BRCA1 involvement

SUMMARY

Researchers noted reduced levels of BRCA1 protein in the brains of mice and deceased Alzheimer’s patients. While this study is interesting early work on the biology of Alzheimer’s disease, the focus was primarily Alzheimer’s disease, rather than the effect of BRCA1 mutations on Alzheimer’s. Therefore, this study’s observation may be something that is seen in Alzheimer’s patients, but does not necessarily cause the disease. No studies suggest that BRCA1 mutation carriers are at increased risk for Alzheimer’s disease. (12/22/2015)

STUDY AT A GLANCE

This study is about:
A potential role for normal BRCA1 protein in Alzheimer’s disease.

Why is this study important?
This study is basic research on Alzheimer’s disease.
Study findings:

1. Mice that do not have BRCA1 protein in their neurons had more DNA damage, smaller neurons, and deficiencies in learning and memory.
2. Brains from deceased patients with Alzheimer’s disease had less normal BRCA1 protein than brains of people without Alzheimer’s.

What does this mean for me?

Currently, no association has been found between BRCA1 mutations and Alzheimer’s disease. While this study provided an interesting laboratory finding—reduced levels of BRCA1 protein in the brains of deceased Alzheimer’s patients—the results are not clinically relevant to people with BRCA1 mutations. Alzheimer’s disease is complex, and many things go wrong with the brain of people with the disease. This study did not show that reduced BRCA1 protein levels cause Alzheimer’s disease, but it did raise the question of whether reduced levels is one of the changes that occur in someone who has Alzheimer’s disease.

This study does NOT show that you have an increased risk of Alzheimer’s if you have a BRCA1 mutation.

Posted 12/22/15

References


FORCE offers many peer support programs for people with inherited mutations.

- Our Message Boards allow people to connect with others who share their situation. Once you register, you can post on the Diagnosed With Cancer board to connect with other people who have been diagnosed.
- Our Peer Navigation Program will match you with a volunteer who shares your mutation and situation.
- Our moderated, private Facebook group allows you to connect with other community members 24/7.
- Check out our virtual and in-person support meeting calendar.
- Join a Zoom community group meeting.
  - LGBTQIA
  - Men
  - American Sign Language
  - People of Color

Updated: 02/05/2022

Forbes
Breast cancer gene BRCA1 may play a role in Alzheimer’s disease

TIME
How a breast cancer gene may affect Alzheimer’s

Medical News Today
Breast cancer gene BRCA1 may be involved in Alzheimer’s disease

How we rated the media
BRCA1 and BRCA2 are involved in repairing errors in DNA. Researchers have seen lots of DNA damage in brains cells of patients with Alzheimer’s disease. Lennart Mucke, M.D and colleagues at the Gladstone Institute of Neurological Disease and the University of California, San Francisco want to understand what DNA repair mechanisms might be involved in that damage. Although DNA damage is not known to cause Alzheimer’s disease, it is seen in Alzheimer’s patients and may be an effect of the disease.

**Researchers of this study wanted to know:**

Whether the DNA damage seen in the neurons of patients with Alzheimer’s could be explained by lower levels of BRCA1 protein.

**Population(s) looked at in the study:**

For the experiments looking at the BRCA1 levels in brains from deceased patients, researchers examined the brains of 8 patients without Alzheimer’s disease and 8 patients with Alzheimer’s disease.

Mice studies were also made:

- mice that were genetically engineered to have some Alzheimer’s disease symptoms.
- mice that were engineered to have less BRCA1 protein.

Each treatment group included 3 to 20 mice for the various experiments.

**Study findings:**

1. Mice that do not have BRCA1 protein in their neurons have more DNA damage, smaller neurons and have deficiencies in learning and memory.
2. Brains from deceased Alzheimer’s disease patients have lower BRCA1 protein levels.

**Limitations:**

The number of patient samples used was small: 8 samples for each group. Most of the experiments were performed in mice, however, test results from mice do not conclusively indicate what will occur in humans. **Importantly, the study only reviewed normal BRCA1 genes and not BRCA1 mutations associated with increased cancer risk.**

**Conclusions:**

While the studies looking at mice without BRCA1 protein appear convincing regarding a potential role for BRCA1 in neuronal function, no published study has associated BRCA1 with Alzheimer’s disease. For many years, researchers have been looking for genetic factors that increase the risk of Alzheimer’s disease—BRCA1 is not a gene that is associated with the disease. **More importantly, no clinical data show that people with BRCA1 mutations have an increased risk for developing Alzheimer’s.**

Some media headlines claim that BRCA1 mutations may affect Alzheimer’s disease, but this cannot be concluded from the study. Everybody is born with 2 copies of the BRCA1 gene. People with BRCA1 mutations have one “bad copy” (the one with the mutation) and one “normal copy.” This Alzheimer’s disease study looked at how normal copies of BRCA1 work in people with Alzheimer’s disease, not how BRCA1 mutations affect Alzheimer’s disease.

According to the National Institute on Aging, Alzheimer’s disease is the most common form of age-related dementia in the United States. Given how common Alzheimer’s disease is—over 5 million Americans currently live with the disease—it is likely that some families will be affected by both BRCA1 mutations and Alzheimer’s disease, but that does not mean that the two are associated.
For now, the reduced levels of BRCA1 in Alzheimer’s patients observed by researchers is only an observation that does not conclude anything about the effects of BRCA1 mutations on the disease. More research needs to be done to understand the role of normal BRCA1 proteins in Alzheimer’s disease, but based on current research there is no reason to believe that BRCA1 mutations carriers are at increased risk of Alzheimer’s disease.
Study: Do parabens in personal care products increase breast cancer risk?

SUMMARY

Parabens are chemicals that can mimic the hormone estrogen in the body. As estrogen has been shown to increase breast cancer risk, some people have asked if parabens found in some cosmetics and shampoos will also increase breast cancer risk. Many studies have shown that parabens in the quantities found in personal care products are safe. A recent study of human breast cancer cells suggests that in certain conditions, parabens could help some breast cancer cells grow. It is important to remember that this is early research; this single laboratory-based study does not conclusively prove that parabens are dangerous. More work, including human studies, needs to be done to understand if parabens increase cancer risk. (01/16/2016)
Whether the parabens, chemicals that mimic estrogen, found in shampoos, body lotions, cosmetics and other personal care products can stimulate growth of HER2+ breast cancer cells, and if so, under what conditions.

**Why is this study important?**

Many household items contain parabens to help prevent microbial or fungal growth in the product.

**Study findings:**

1. Using human breast cancer cells that were estrogen receptor-positive (ER+) and human epidermal growth factor receptor 2-positive (HER2+), researchers found that in the laboratory, parabens stimulated growth in both types of cells.

2. Growth in breast cells containing the molecule that activates HER2(+) was stimulated by fewer parabens than cells that did not contain the molecule.

**What does this mean for me?**

The [FDA](http://www.fda.gov) website currently states: "At the present time there is no reason for consumers to be concerned about the use of cosmetics containing parabens. However, the agency will continue to evaluate new data and will advise the public of risks if any are found."

This study DID NOT conclude that parabens found in cosmetics or shampoos cause breast cancer or even increase the risk of breast cancer. It involved human cancer cells that were taken from a woman with invasive breast cancer and then cultured in a laboratory. This means two things:

1. The cells used in this study are different than human breast cells found in the body, and

2. More human studies involving live organisms need to be done to determine breast cancer risk.

However, if avoiding parabens is important to you, you might want to choose from the many personal care products (cosmetics, shampoos, etc.) that do not contain parabens.

**References**


Disclosure
FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

IN DEPTH REVIEW OF RESEARCH
Study background:
Estrogen is known to promote breast cancer by binding to estrogen receptors in the breast. Because of this well-established association, there is a lot of concern about “estrogen mimickers,” chemicals that can bind to estrogen receptors in the body. Parabens are estrogen mimickers that are used in many personal care products, including cosmetics, shampoos, and sunscreens, to prevent microbial and fungal growth in the products. Previous studies showed that even though parabens are estrogen mimickers, they bind to estrogen receptors very weakly, and cannot cause cells to become cancerous. For this reason, the FDA has deemed parabens to be safe for use.

https://www.facingourrisk.org/XRAY/parabens-and-breast-cancer-risk
In October of 2015, Dale Leitman and colleagues at the University of California, Berkeley published a study in the journal Environmental Health Perspectives that looked at the ability of parabens to stimulate the growth of breast cancer cells. The study authors feel this is important because previous studies only looked at the ability of parabens to encourage cell growth in an environment that did not include human epidermal growth factor receptor 2 (HER2) and the molecule that activates it, which is present in some breast cancers.

Researchers of this study wanted to know:

Whether parabens can stimulate breast cancer cell growth when the HER2 receptor and the molecule that activates it are present.

Population(s) looked at in the study:

This study did not include humans. Rather, it used invasive breast cancer tumor cells taken from a woman; researchers grew the cells in special dishes in the laboratory that provided all of the nutrients a cell needs to grow and divide. The cells included both estrogen receptor (ER+) and human epidermal growth factor receptor 2 (HER2+). Cells from women with ER+/HER2- and ER-/HER2+ breast cancers were used for comparison.

Study findings:

1. Using human breast cancer cells that were estrogen receptor-positive (ER+) and human epidermal growth factor receptor 2-positive (HER2+), parabens stimulated cell growth in the laboratory.

2. Growth in breast cells containing the molecule that activates HER2 was stimulated by fewer parabens than cells that did not contain the molecule.

Limitations:

This study isolated one patient’s ER+ and HER2+ invasive breast cancer tumor cells and then grew them in the laboratory. Studies involving cells have some general limitations. One is that although researchers try to mimic the cells’ environment in the body, it is not possible to do this perfectly. The cells in this study were observed in isolation: they were not surrounded by different types of cells and organs normally found in the body, nor were they potentially affected by what would be going in the body at any given time. Studies like this that use laboratory-grown cells are considered to be very early steps in the research process, and do not necessarily translate to what will happen in humans.

It is also important to note that the cells used in this study were from a woman with invasive breast cancer; they do not represent what occurs in people without cancer. Study authors did not note whether the cell donor had mutations in BRCA1 or other genes that increase breast cancer risk.

Conclusions:

Research done with cells has limitations, but it is still an important first step in the research process. As such, these studies point to ideas that should be studied further in a more biologically relevant environment. While it is possible that the cell findings could be important for humans, it is also possible that the cell findings will not be replicated in other cells or in studies on living organisms. This study indicates that more work needs to be done to determine whether parabens can increase breast cancer cell growth and potentially increase cancer risk, as noted in many media reports, but it will take more studies to show if this is the case.

Posted 1/12/16
Study: Does lumpectomy or mastectomy provide better survival for women with early stage breast cancer?

**Summary**

Previous research has hinted that women who have breast-conserving surgeries have the same, if not better, overall survival as women who have mastectomies. Researchers in this study wanted to see if that was true; they found that women who chose breast-conserving surgeries did have a higher overall survival. However, this study, presented at the 2015 San Antonio Breast Cancer Symposium, had limitations that make it difficult to interpret the results or to extend them to all women with breast cancer. (01/19/2016)

**STUDY AT A GLANCE**

This study is about:

Whether survival is better for women with early-stage breast cancer who opted for breast-conserving surgery (surgery that only removes part of the breast, such as a lumpectomy) compared to women who had mastectomies.

This article is relevant for:

- Women with early stage breast cancer
- Triple negative breast cancer
- ER/PR +
- Her2+ breast cancer
- Breast cancer survivors

https://www.facingourrisk.org/XRAY/survival-lumpectomy-versus-mastectomy
Why is this study important?
Knowing the positives and negatives of the surgical options for women who are diagnosed with early-stage breast cancer is important. For example, research has shown that women who have mastectomy and reconstruction have many more complications than women who opt for lumpectomy and whole breast irradiation. Also, the cost of breast-conserving surgery is usually less than the cost of mastectomy. But which surgery has better survival? That is one of the most important things to consider when deciding on a surgical treatment.

Study findings:
1. Women who had breast-conserving surgery had increased 10-year survival compared to women who got mastectomies.

What does this mean for me?
While this data is interesting, it does not change care guidelines for women with early-stage breast cancer. Women should still decide what surgery they want based on their personal preference and all of the characteristics of their cancer. It is important to note that this study did not take into consideration whether or not the women had mutations in BRCA1 or other genes that are associated with an increased risk of a second breast cancer.

Posted 1/19/16

References

Disclosure
FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

TIME

With early breast cancer treatment, less may be more: studies

The Washington Post

Breast-conserving surgery plus radiation increases survival rates for women with early-stage cancer

Health Day

Lumpectomy plus radiation may beat mastectomy for early breast cancer

General Surgery News

More evidence supports breast conservation over mastectomy

Medscape

Ten-year data: Lumpectomy and radiotherapy trump mastectomy

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Research from the 1980s showed that survival is the same after breast-conserving surgery with radiation therapy or mastectomy. Current studies show that survival may be better for women who have breast-conserving surgery with radiation therapy.

In December 2015, Dr. Marissa van Maaren from the Netherlands Comprehensive Cancer Organization presented “Higher 10-year overall survival after breast conserving therapy compared to mastectomy in early stage breast cancer: A population-based study with 37,207 patients” at the San Antonio Breast Cancer Symposium. This study by Dr. van Maaren and her colleagues looked at the differences in survival between breast-conserving surgery and mastectomy.

Researchers of this study wanted to know:
What is the difference in 10-year overall and distant metastasis-free survival after breast-conserving surgery compared to mastectomy for women with early-stage breast cancer?

Population(s) looked at in the study:

https://www.facingourrisk.org/XRAY/survival-lumpectomy-versus-mastectomy
This study used information about 37,207 women from the Netherlands Cancer Registry. Researchers selected women with a first primary breast cancer tumor (up to five centimeters, with no more than three positive lymph nodes) diagnosed between 2000 and 2004. About 58% of the women were treated with breast-conserving surgery and radiation therapy; the remainder had mastectomy without radiation. While all of the data from the women were used for the overall survival data analysis, only data from women who were diagnosed in 2003 was used for the distant metastasis-free survival data analysis.

**Study findings:**

1. Women who had breast-conserving surgery had approximately 20% increased overall survival compared to women who had mastectomy.

2. Women with small tumors that had not spread to the lymph nodes, and had breast-conserving surgery had a better 10-year distant metastasis-free survival rate than those who had mastectomy.

**Limitations:**

The researchers noted that overall, patients in the breast-conserving surgery group were younger and had more favorable prognoses, which may have influenced the study outcome. A bigger issue is that the breast-conserving surgery patients also had radiation therapy, while the mastectomy patients did not, so whether or not the increased survival rate was directly due to radiation therapy in the breast-conserving therapy group cannot be conclusively stated. Also, it is important to note that the BRCA mutation status of the women was not reported, so we do not know if BRCA carriers who had a higher risk of a second cancer opted for mastectomy.

**Guidelines:**

**Conclusions:**

While this study supports previous data that says that overall survival is at least the same, if not better, with breast-conserving surgery, not enough conclusive proof exists to change guidelines. A larger prospective trial would be needed to determine which surgery provides better survival. Some patients may benefit much more from mastectomies than others, and some may benefit more from breast-conserving surgery. More work needs to be done to tease out these results.

Posted 01/19/16

**SEARCH XRAY STUDIES AND ARTICLES**

Keyword:  

Cancer Type:  

Choose:  

Relevant for:  

Choose Cancer Type First...
Study: Potential genetic basis for breast cancer survivors who develop therapy-related leukemia

**SUMMARY**

The population of breast cancer survivors in the United States is increasing. One rare but dangerous long-term effect of breast cancer treatment is an increased risk of leukemia, a type of bone marrow cancer. A recent study uncovered a potential genetic basis for this condition. (01/26/2015)

**STUDY AT A GLANCE**

**What is this study about?**

This study explores whether inherited mutations in genes that increase cancer risk are risk factors for developing leukemia after therapy. Therapy-related leukemia is a rare, late complication that develops in less than 1% of breast cancer patients who receive cytotoxic cancer therapies such as chemotherapy or radiation.

https://www.facingourrisk.org/XRAY/therapy-related-leukemia
Why is this study important?

Although treatment-related leukemia is rare, the majority of people who develop the disease are breast cancer survivors. This is a rare complication, but the number of therapy-related leukemia cases will likely increase as more patients survive breast cancer. A greater understanding is needed of who is at risk for the development of therapy-related leukemia, so that better detection and prevention of this potentially lethal complication can be established. In a large study published in the Journal of Clinical Oncology in 2014, among 20,000 patients who had stage I to III breast cancers treated with various therapies, only 50 survivors developed leukemia after follow-up periods ranging from 6 months to 10 years (median follow-up was about 5 years).

What did this study find?

Of the 47 breast cancer survivors who received cytotoxic therapy and developed therapy-related leukemia and had available DNA for mutation testing, about 20% had a mutation in a cancer-risk increasing gene:

- 3 patients had mutations in BRCA1
- 2 patients had mutations in BRCA2
- 3 patients had mutations in TP53
- 1 patient had a mutation in CHEK2
- 1 patient had a mutation in PALB2

Limitations:

This study is relatively small, so the researchers cannot see potential differences in therapy-related leukemia between people with mutations in different genes (for example, BRCA mutation carriers compared to TP53 mutation carriers). Because the group of patients studied was small, individuals with different types of breast cancers and different treatments were grouped together, making it harder to clearly identify groups at risk.

What does this mean for me?

The data from this research indicates that a inherited mutation in a gene that increases cancer risk may lead to susceptibility to therapy-related leukemia, however, more work needs to be done to fully understand this finding. It is important to remember that treatment-related leukemias are rare. If you are a BRCA1, BRCA2, TP53, CHEK2, or PALB2 mutation carrier, and you have received a cytotoxic therapy such as chemotherapy or radiation, you may wish to discuss this risk for treatment-related leukemia with your health care provider. If you are a breast cancer survivor who developed therapy-related leukemia and you are unsure if you are a carrier of a mutation that increases cancer risk, talk to your health care provider about the possibility of genetic counseling and/or genetic testing to see if you carry such a mutation.
Although this research focused on breast cancer survivors, these findings may also be relevant for people with inherited mutations who have received chemotherapy for other types of cancers.

Posted 1/26/15

(back to top)
References


WHO COVERED THIS STUDY?

HealthDay
Researchers focus on risk factors for leukemia after breast cancer treatment

Latinos Health
Breast cancer survivors at risk of getting leukemia: study

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Chemotherapy and radiation can help patients defeat their cancers, but many complications can occur during and after treatment. Breast cancer survivors are a growing population in the United States, and while they have survived their disease, they often face long-term complications and side effects. One example is developing therapy-related leukemia, a rare but potentially lethal complication of some cancer treatments.

In December 2015, Jane E. Churpek and colleagues at the University of Chicago published a study in Cancer that looked to see if inherited genetic mutations are linked to the development of therapy-related leukemia. Researchers and clinicians believe that therapy-related leukemia develops from cytotoxic therapies such as chemotherapy and radiation that cause mutations in blood cell DNA, but they do not understand why this happens to certain patients.
and not to others. Some breast cancer patients who are treated with surgery alone develop leukemia—this raises the possibility that some cancers that are identified as therapy-related leukemia are actually second primary cancers caused by inherited mutations in genes that are associated with increased cancer risk.

Currently, no study has looked at the possibility of increased risk for therapy-related leukemia in people who carry mutations in genes that increase cancer risk.

What researchers of this study wanted to know:

Are inherited cancer risk-increasing gene mutations involved in the development of therapy-related leukemia in breast cancer survivors?

Population(s) looked at in the study:

The study included 88 female breast cancer survivors who received cytotoxic therapy (chemotherapy and/or radiation) after their primary breast cancer diagnosis, and later developed therapy-related leukemia. Family history and/or DNA samples for genetic testing were available for patients in the study, and genetic testing was done whenever possible.

Study findings:

1. Of the 47 breast cancer survivors who received cytotoxic therapy and developed therapy-related leukemia and had available DNA for mutation testing, about 20% had a mutation in a cancer-risk increasing gene:
   - 3 patients had mutations in BRCA1
   - 2 patients had mutations in BRCA2
   - 3 patients had mutations in TP53
   - 1 patient had a mutation in CHEK2
   - 1 patient had a mutation in PALB2

2. About 20% of the study population had an additional primary cancer and therapy-related leukemia.

3. Of the 70 patients for whom researchers had family histories, about 60% had a close relative who had breast, ovarian, or pancreatic cancer.

Limitations:

This study is relatively small, so the researchers cannot see potential differences in therapy-related leukemia between people with mutations in different genes (for example, BRCA mutation carriers compared to TP53 mutation carriers). Because the group of patients studied was small, individuals with different types of breast cancers and different treatments were grouped together, making it harder to clearly identify groups at risk. Additionally, while this study shows that about 1 in 5 women who developed treatment-related leukemia after cytotoxic therapy for breast cancer had a mutation in a gene known to increase cancer risk, this group was not compared to mutation carriers who were treated with cytotoxic therapy but did not develop therapy-related leukemia; doing so would have provided additional information.

Conclusions:

This study uncovers a potential link between having a mutation in a gene that increases cancer risk and susceptibility to developing therapy-related leukemia after receiving cytotoxic therapy for breast cancer. More work needs to be done to fully understand this, and to learn how therapy-related leukemia develops in these women. In the meantime, breast cancer survivors with mutations in BRCA or other genes that increase cancer risk should keep in mind that treatment-related leukemia is relatively rare, occurring in fewer than 1% of breast cancer survivors. Notably, 3 of the
47 patients with treatment-associated leukemia had inherited mutations in TP53, which is already associated with increased risk for leukemia. While this study raises the possibility of a link that should be explored further through larger studies, the results alone cannot conclude that mutation carriers are more likely to develop therapy-related leukemia than non-mutation carriers. People concerned about their risk of leukemia after treatment should discuss their risk with their health care provider.

Posted 1/26/15

SEARCH XRAY STUDIES AND ARTICLES

Keyword:

Cancer Type:

Choose

Relevant for:

Choose Cancer Type First...

Categories:

- Alternative Treatments
- Basic Science
- Cancer Diagnosis
- Cancer Risk
- Cancer Treatment
- Clinical Trials
- Emotional Health
- Environmental Exposure
- Family & Caregivers
- Financial Issues
- Genetic Testing
- Health Disparities
- Health Literacy
- Hereditary Cancer
- Intimacy & Body Image
- LGBTQIA+
- Male Breast Cancer
- Menopause
- Metastatic Cancer
- Nutrition & Exercise
- Palliative Care
- Pregnancy & Fertility

https://www.facingourrisk.org/XRAY/therapy-related-leukemia
Study: Sugar promotes tumor growth and metastasis in mouse model breast cancer

SUMMARY

Previous human studies found associations between high sugar intake and breast cancer risk. This study looked at the direct effect of sugar on breast cancer growth and metastasis in mice. While researchers observed that sugar increased tumor growth and metastasis, more work needs to be done to see if this finding is relevant in humans. It is important to remember, the overall health benefits of limiting sugar intake remain undisputed. (02/02/16)

This article is relevant for:

- People diagnosed with breast cancer

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- Join the FORCE mailing list
- Search by category, keyword or date
This is an early step in understanding how high sugar intake might affect breast cancer growth and development.

**Study findings:**

1. Sucrose (table sugar) intake increased tumor growth and metastasis in a mouse model of breast cancer.

**What does this mean for me?**

This study was done in a mouse model of breast cancer. Researchers expected that about half of the mice would develop breast cancer in the course of the experiment. While these types of early laboratory studies in mice are important for scientists trying to understand how cancer develops and spreads, they are not directly applicable to humans. It is important to remember that while the researchers tried to match the sugar levels the mice received to those found in Westernized diets, the rest of the mouse diet was not comparable to an average person’s diet.

The dangers of consuming excessive amounts of sugar are well established—the American Heart Association recommends that men and women consume no more than 37.5g and 25g of sugar, respectively. While this study does not conclusively show that sugar should be avoided or that excess sugar causes breast cancer to occur or spread, the overall health benefits of limiting sugar intake remain undisputed.

Posted 2/2/16

**References**


Learn more about XRAY
WHO COVERED THIS STUDY?

**NBC News**
*Here's how sugar might fuel the growth of cancer*

**Medical Daily**
*Breast cancer tumors may be influenced by daily sugar intake: How the sweet stuff increases cancer risk*

**Newsmax**
*Sugar increases risk and spread of breast cancer*

**Fox News**
*Sugar may increase breast, lung cancer risk, study finds*

**Daily Mail**
*Sugar in fizzy drinks and junk food increases chances of breast cancer and its spread to other organs, scientists claim*

How we rated the media

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**IN DEPTH REVIEW OF RESEARCH**

**Study background:**

Previous studies in humans have found associations between high sugar intake and breast cancer risk, including a recent study that found that increased consumption of sugar-sweetened beverages is a contributor to worldwide obesity, heart disease, and cancer. However, no study has directly studied whether a high-sugar diet can cause breast cancer to grow and/or affect breast cancer metastasis.

In January 2016, Yan Jiang and colleagues at the University of Texas MD Anderson Cancer Center published a paper in the journal *Cancer Research* looked at breast cancer development, growth, and metastasis in mice with various amounts of table sugar in their diets. This is the first study to look at a direct effect of consuming sugar and breast cancer development using mouse models of breast cancer.

**Researchers of this study wanted to know:**

Whether sugar consumption led to breast tumor growth and metastasis in mouse models of breast cancer.

**Population(s) looked at in the study:**
This study used two well-established mouse models of breast cancer. The first is a model in which 50% of the mice are known to develop tumors after six months under normal conditions. The second is a model in which breast cancer metastasizes to the mouse lung.

**Study findings:**

Compared to mice than did not consume sugar, mice that did consume sugar:

1. developed more tumors.
2. had a higher number of lung metastases.
3. had significant quantities of a protein known as 12-LOX—which provides a clue to cellular changes that might have caused tumors to grow in response to sugar.

**Limitations:**

While this is the first study to look directly at the effect of sugar on tumor growth, more work is needed to determine whether the same effect occurs in humans. It is important to note that close to half of the mice in the study would have developed tumors after six months regardless of the amount of sugar they ate. While they were fed an amount of sugar that is equivalent to a Westernized diet, other nutrients in their diet were not the same as in a Westernized human diet.

**Conclusions:**

This study suggests that sugar may play a role in breast tumor growth and metastasis. It does not, however, implicate sugar or a particular amount of sugar as a cause of breast cancer. It is important to remember that this is early research in mice and more work needs to be done to understand this effect in humans. Although limiting sugar consumption is recommended for overall health, the data from this study does not provide enough evidence for people to stop consuming sugar entirely to reduce their risk of breast cancer development, growth, or metastasis.

Aside from the results of this study, everybody should limit sugar consumption, as recommended by the American Heart Association; your own personal or family health history may dictate that you follow more specific health guidelines. If you are concerned with how your diet affects your cancer or cancer risk, please discuss your options with your health care provider.

Posted 2/2/16

**SEARCH XRAY STUDIES AND ARTICLES**

Keyword:  
Cancer Type:  
Choose

Relevant for:  
Choose Cancer Type First...
Study: How do ultrasound and mammography compare in breast cancer screening?

SUMMARY

Mammography has been shown to reduce breast cancer deaths; however, women in developing countries don’t have easy access to mammography. Ultrasound screening, on the other hand, is portable and less expensive, and could be an alternative to mammography. This study compared mammography to ultrasound in women with dense breasts and found the two techniques have similar cancer detection rates, although the false positive rate is higher with ultrasound. (02/16/16)

STUDY AT A GLANCE

What is this study about?
The study looks at the effectiveness of ultrasound as compared to mammography for breast cancer screening.
**Why is this study important?**

In general, the number of breast cancer cases worldwide is increasing. Women in developing countries do not have easy access to mammography, and some lack breast cancer screening entirely. Ultrasound has many advantages: it does not use ionizing radiation, the machinery is portable and not as expensive as mammography, making it a more viable alternative for women in developing countries.

**What did this study find?**

- A total of 111 breast cancers were found in three years. (The study included a total of 7473 breast cancer screens in patients at increased risk for breast cancer.) Of these 111 breast cancers, 58 were found through ultrasound and 59 were found through mammography.
- There were more false positives among the patients who got ultrasounds compared to patients who got mammography. The recall rate for ultrasounds was about 11% while the recall rate for mammograms was about 9%.

**What does this mean for me?**

Ultrasound and mammography have similar cancer detection rates, although there are more false positives found through ultrasound. However, this finding does not mean that ultrasound should replace mammography. According to the study authors, “…these results suggest that screening [ultrasound] could be a viable alternative to mammography in countries lacking organized screening, particularly with availability of low-cost, portable [ultrasound] systems. Where mammography is available, [ultrasound] should be seen as a supplemental test for women with dense breasts who do not meet high-risk criteria for screening MRI (I) and for high-risk women with dense breasts who are unable to tolerate MRI.” National guidelines recommend that women who have mutations in BRCA (I) or other genes that increase their risk of breast cancer undergo increased surveillance for breast cancer using both MRI and mammography. It is important to remember that this study looked at women at high risk for breast cancer. The results may not apply to women with an average lifetime risk of breast cancer.

Posted 2/16/16

**References**

Berg WA, Bandos AI, Mendelson EB, et al. "Ultrasound as the Primary Screening Test for Breast Cancer: Analysis from ACRIN 6666." Journal of the National Cancer Institute. Published online first on December 28, 2015.

**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Board.
WHO COVERED THIS STUDY?

Reuters
Ultrasound may be useful supplemental test for breast cancer ★★★★★

HealthDay
Breast ultrasound, mammography may be equally effective: study ★★★★★

HeraldNet
Study: Add ultrasound in cancer fight for some ★★★★★

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Previous work has shown that mammograms reduce the number of breast cancer deaths. In women from age 40-49, researchers have seen a 15% reduction in breast cancer deaths; a 22% reduction has been seen in women from age 50 -74. It is believed that older women benefit more from mammography because their breasts are not as dense as those of younger women. In addition to ultrasound’s portability and cost benefits, the quality of ultrasound images are not as limited by breast density as are mammography images.

In January 2016, Wendie Berg and colleagues at the Magee-Womens Hospital of University of Pittsburgh Medical Center and other institutions published a study in the Journal of the National Cancer Institute that compared all aspects of cancer detection from ultrasound and mammography.

What researchers of this study wanted to know:
Is ultrasound a viable alternative to mammography?

Population(s) looked at in the study:
This study included 2,662 women who did not have breast cancer, but did have dense breasts. These women also had to have one other risk factor for breast cancer (for example, a BRCA mutation, an atypical breast biopsy, or high risk scores through the Gail test for Breast Cancer Risk Assessment).

Study findings:
1. One hundred and eleven breast cancers were found in a three-year period from a total of 7473 breast cancer screens in patients at increased risk for breast cancer. Of these 111 breast cancers, 58 were found through ultrasound and 59 were found through mammography.
2. It took 129 ultrasound screens to detect 1 cancer.
3. It took 127 mammogram screens to detect 1 cancer.
4. 89 of the breast cancers were invasive. Of the 89 invasive cancers, 53 were found by ultrasound and 41 were
found by mammography.

- Fifty-three of the 58 cancers found by ultrasound were invasive; the other five were ductal carcinoma in situ (DCIS). Forty-one of the 59 cancers found by mammogram were invasive; the other 18 were DCIS. These results indicate that ultrasound screening may be better able to identify invasive cancers.

5. There were more false positives found in patients who got ultrasounds compared to patients who got mammograms. The recall rate for ultrasounds was about 11% while the recall rate for mammograms was about 9%.

- The biopsy rate for the women who got called back based on their ultrasound results was about 6% while it was 2% for women who got called back based on their mammogram results.

**Limitations:**

In order to participate in this study, women had to have dense breasts and at least one other risk factor for breast cancer, meaning that they were all at greater risk for breast cancer than women in the general population. Therefore, the results of this study may be more applicable to young breast cancer survivors. Had study participants been at average risk for breast cancer, the results may have been different. For now, the results apply only to women at high risk of breast cancer.

**Conclusions:**

This study suggests that ultrasound may be a viable alternative to mammography for women in countries that do not have access to mammography. Ultrasound should not be a replacement, however, for women who can access mammography. The researchers saw that more invasive cancers were detected by ultrasound as compared to mammography; however, they write, "a larger study is needed to statistically support greater sensitivity of ultrasound to invasive cancers."

Posted 2/16/16

**SEARCH XRAY STUDIES AND ARTICLES**

Keyword:  
Cancer Type: 
Choose

Relevant for: 
Choose Cancer Type First...

Categories:  
- Alternative Treatments
- Basic Science
- Cancer Diagnosis

https://www.facingourrisk.org/XRAY/ultrasound-vs-mammogram-for-breast-screening
Study: Smoking before or after a breast cancer diagnosis associated with poorer breast cancer survival

SUMMARY

Cigarette smoking is an important public health issue that causes more than 480,000 deaths annually. Smoking increases the risk of many diseases, from heart disease to stroke. This research indicates that smoking before and or after a diagnosis of breast cancer affects survival, and also shows that it is never too late to quit smoking. (02/23/16)

STUDY AT A GLANCE

This study is about:

How cigarette smoking before and/or after a diagnosis of breast cancer affects breast cancer survival and other smoking-related diseases.

Why is this study important?
While experts may not have enough evidence to confirm a direct relationship between smoking and breast cancer, the 2014 Report of the Surgeon General on the health consequences of smoking suggested that smoking may cause breast cancer. Beyond the risk of breast cancer, cigarette smoking is an important public health issue. It increases the risk of heart disease, stroke, lung cancer, overall diminished health, and causes more than 480,000 deaths in the U.S. each year.

**Study findings:**

1. Women who smoked one year before their breast cancer diagnosis were more likely to die of breast cancer than women who never smoked.
2. Women who quit smoking after their breast cancer diagnosis were less likely to die from breast cancer than women who continued to smoke after diagnosis.

**What does this mean for me?**

While no studies directly implicate cigarette smoking as a cause of breast cancer, this study found that smoking appears to affect breast cancer mortality. Researchers saw a benefit for women who quit smoking after their breast cancer diagnosis; that is promising, showing that quitting smoking, even later rather than sooner, can improve health.

Additionally, cigarette smoking has harmful health effects throughout the body. Women and men who smoke should get whatever help they need to quit.

Posted 2/23/16

**References**

CDC. Fact Sheet: [Health Effects of Cigarette Smoking](https://www.cdc.gov/tobacco/fact_sheets/health effects_cigarettes.html)


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our [Scientific Advisory Board](https://facingourrisk.org/about/our-board) prior to publication to assure scientific integrity.
IN DEPTH REVIEW OF RESEARCH

Study background:
Previous research linked cigarette smoking before breast cancer diagnosis to lower breast cancer survival but little is known about how smoking after a breast cancer diagnosis affects breast cancer survival.

In January 2016, Michael Passarelli and colleagues from the University of California, San Francisco and other institutions published a study in the Journal of Clinical Oncology about how smoking before and after a breast cancer diagnosis affects breast cancer survival.

Researchers of this study wanted to know:
Whether an association exists between breast cancer survival and smoking before or after a diagnosis of breast cancer.

Population(s) looked at in the study:
About 21,000 women from the Collaborative Breast Cancer Study (CBCS) participated in this study and:

- had invasive breast cancer.
- were between the ages of 20-79.
- were from Wisconsin, New Hampshire, and Massachusetts.
The women were asked several key questions about smoking: whether they had smoked at least 100 cigarettes during their lifetime, when they started, how long they had been smoking, the average number of cigarettes they smoked each day, whether they had smoked one year before they were diagnosed with breast cancer, if they currently smoked, and (for the women who had quit) the age they quit.

About 15,000 women from the CBCS study were invited to participate in the Collaborative Women’s Longevity Study (CWLS). The women who completed the survey were all breast cancer survivors and were an average of 6 years post-breast cancer diagnosis. This questionnaire asked the women for information about their post-diagnosis exposures and health events.

Study findings:

1. Women who smoked one year before their breast cancer diagnosis had a 25% increased risk of dying from their breast cancer than women who never smoked. About 14% of women who had never smoked died from breast cancer compared to about 17% of women who smoked one year before they were diagnosed.
   - Women who smoked one year before their breast cancer diagnosis were:
     - 14 times more likely to die of respiratory cancer than women who had never smoked. Less than .5% of women who had never smoked died from respiratory cancer compared to about 4% of women who smoked one year before they were diagnosed with breast cancer.
     - 2 times more likely to die of cardiovascular disease than women who had never smoked. About 6.5% of women who had never smoked died from cardiovascular disease compared to about 8% of women who smoked one year before they were diagnosed with breast cancer.

2. Women who quit smoking after their breast cancer diagnosis had a 33% decreased risk of dying from breast cancer than women who continued to smoke after diagnosis. This means that women who quit smoking post-breast cancer diagnosis were more likely to survive than the women who kept smoking.

3. 10% of women in the study reported that they kept smoking after their diagnosis. These women had a 72% increased risk of dying from breast cancer than women who never smoked. Using the data from the CWLS population, about 5% of women who had never smoked died from breast cancer compared to about 8% of women who were still smoking.

Limitations:

Conducting a study based on responses from a self-reported questionnaire has limitations. It is possible that some women may not have accurately presented their smoking status. The study design allowed only one opportunity to follow up with the smoking status of women after diagnosis; because the study represents only a snapshot, it may not have been entirely accurate.

Nor did this study take into account the hormone receptor status of breast tumors, or whether or not women had a mutation in BRCA1 or another gene that increases cancer risk; whether these factors combined with smoking affect breast cancer survival—and to what extent—is unknown.

Conclusions:

This research provides evidence that smoking affects breast cancer survival before and after a breast cancer diagnosis, and showing that quitting after breast cancer diagnosis has benefits. However, according to the study authors, “Regardless of a diagnosis of breast cancer, smokers should undergo recommended respiratory and cardiovascular disease surveillance to reduce smoking-related survival.”
Study: What are the genetics underlying 12 different cancer types?

SUMMARY

As gene sequencing has become more affordable, researchers and health care providers are now looking for mutations in many genes beyond BRCA1, BRCA2 and others that are associated with known hereditary cancer syndromes. By sequencing thousands of genes rather than just one or two, researchers can better understand which inherited mutations affect cancer risk. In this study, researchers sequenced thousands of genes in patients with one of 12 cancers, including breast, and catalogued which gene mutations are most commonly found in each cancer. (03/01/16)

STUDY AT A GLANCE

This study is about:
Inherited gene mutations found in some patients with one of 12 different cancers.

Why is this study important?

This article is relevant for:

- People diagnosed with cancer

This article is also relevant for:

- Previvors
- People with a genetic mutation linked to cancer risk
- People with a family history of cancer
Researchers believe that at least 3% of all cancer cases have a strong hereditary component. One example is BRCA mutations, which greatly increase the risk of breast cancer. Other gene mutations also increase cancer risk, but not to the same extent as BRCA. Understanding how often gene mutations that confer moderately higher cancer risk occur in patients is a priority, as these mutations can still be passed to sons and daughters, and may affect patients’ treatment decisions. According to the study authors, “Such discovery of new cancer susceptibility genes...will be an important step towards generating an actionable catalogue for personalized treatment of cancer.”

**Study findings:**

1. The most commonly mutated genes that increase cancer risk are: BRCA1, BRCA2, ATM, BRIP1, and PALB2.
2. The percentage of patients with gene mutations that increase cancer risk varies among cancers. For example, 19% of ovarian cancer patients in this study had an inherited mutation that increases cancer risk, compared to only 4% of acute myeloid leukemia patients.

**What does this mean for me?**

This study identifies and catalogues gene mutations that increase a person’s susceptibility to cancer. Ultimately, the goal is to understand which mutations are clinically relevant and how they increase cancer susceptibility, so that health care providers can determine their patients’ cancer risks and treatment plans. However, we have no national guidelines on how to care for patients with some of the newly discovered mutations, or for patients with mutations that have been studied less extensively than BRCA mutations or the mutated genes that cause Lynch syndrome. This study is an important step in helping researchers get a complete understanding of the role that inherited mutations play in different cancers. But more work needs to be done to fully assess the clinical relevance of these findings. Patients with mutations in genes that do not have national guidelines outlining risk management options should work with their health care providers to determine appropriate treatments and screenings for themselves and their families.

Posted 3/1/16

Share your thoughts on this XRAYS article by taking our brief survey.

**References**


**Disclosure**
FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

The National Comprehensive Cancer Network has guidelines on who should undergo genetic counseling and testing. If you have been diagnosed with breast cancer, you should speak with a genetics expert about genetic testing if any of the following apply to you:

- You have a blood relative who has tested positive for an inherited mutation
- You have any of the following:
  - Breast cancer at age 50 or younger
  - Male breast cancer at any age
  - Ovarian cancer at any age
  - Triple-negative breast cancer at any age
  - Two separate breast cancer diagnoses
  - Eastern European Jewish ancestry and breast cancer at any age
  - Metastatic breast cancer
  - Testing of your tumor shows a mutation in a gene that is associated with hereditary cancer
  - HER2-negative breast cancer and high risk for recurrence
  - Lobular breast cancer and a family history of diffuse gastric cancer

OR

- You have one or more close family members who have had:
  - Young-onset or rare cancers
  - Breast cancer at age 50 or younger
  - Triple-negative breast cancer
  - Male breast cancer, ovarian cancer, pancreatic cancer, or metastatic prostate cancer at any age
  - Two separate cancer diagnoses
  - Prostate cancer at age 55 or younger or metastatic prostate cancer

The American Society of Breast Cancer Surgeons (ASBrS) released guidelines in 2019 that recommend all women diagnosed with breast cancer have access to genetic testing for inherited mutations in breast cancer genes.

https://www.facingourrisk.org/XRAY/genetics-of-different-cancer-types
The following organizations have resources related to genetic counseling and testing.

- **FORCE related resources:**
  - Information: [What is genetic testing?](#)
  - Information: [How to get genetic testing](#)
  - Information: [Hereditary cancer, genes and risk](#)
  - Personalized portal: [Genetic testing](#)
  - XRAY category: [Genetic testing](#)
  - Video: [ABC of Cancer Genetics](#)
  - Video playlist: [Genetic testing](#)
  - Blogs: [Genetic testing](#)
  - **National Society of Genetic Counseling**
  - **JScreen**

*Updated: 12/05/2021*

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**WHO COVERED THIS STUDY?**

**New York Post**

[Scientists say cancer susceptibility is genetic](#) ★★★★★ ★★★

**Daily Mail UK**

[Revealed... 12 cancers that ARE inherited - and how the 'Angelina Jolie gene' could also trigger stomach and prostate tumors](#) ★★★★★ ★★★

**Oncotherapy Network**

[Investigators identify patterns of rare germline variants in 12 cancer types](#) ★★★★★ ★★★

**Medical News Today**

[Study reveals how hereditary gene mutations affect risk of certain cancers](#) ★★★★★ ★★★

**How we rated the media**

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**IN-DEPTH REVIEW OF RESEARCH**

**Study background:**
Some inherited gene mutations confer an extremely high risk of cancer, while others moderately increase cancer risk. In families with mutations in genes that moderately increase cancer risk, determining that cancer is hereditary may be more difficult. However, improved and more affordable genetic sequencing is helping researchers to learn more about these types of mutations.

In December 2015, Li Ding and colleagues from the Washington University School of Medicine in St. Louis and other institutions published in *Nature Communications* their study of gene mutations in cancer patients with one of 12 different types of cancer. Rather than sequencing a handful of genes known to be involved in cancer risk, the researchers used data from “exome sequencing,” which looks at the sequence of all genes used in the cell. Researchers then analyzed the data to find which mutations were inherited and known to be involved in cancer risk. This provides a more comprehensive catalog of the types of inherited gene mutations found in patients with these 12 types of cancer.

**Researchers of this study wanted to know:**

How genetics contributes to cancer development.

**Population(s) looked at in the study:**

The study looked at the DNA sequences from 4,034 patients: about 88% of the patients were Caucasian, about 6% were African American, about 5% were Asian, and .4% were American Indian/Alaska Native. On average, patients were diagnosed at about 60 years old with one of the following 12 types of cancer:

- Breast cancer
- Glioblastoma, a type of brain cancer
- Low grade glioma, a type of brain cancer
- Head and neck cancer
- Kidney renal clear cell carcinoma
- Acute myeloid leukemia, a type of blood cancer
- Two different types of non-small cell lung cancer
- Ovarian cancer
- Prostate cancer
- Stomach cancer
- Uterine cancer

**Study findings:**

1. Among the 12 cancers in this study, *BRCA1*, *BRCA2*, *ATM*, *BRIP1*, and *PALB2* genes were most associated with cancer predisposition.
   - The most commonly detected inherited gene mutations in breast cancer patients were in *BRCA1*, *BRCA2*, *FANCM*, and *ATM*.
   - The most commonly detected inherited gene mutations in ovarian cancer patients were in *BRCA1*, *BRCA2*, *PIK3C2G*, *PALB2*, *CNKSR1*, *BRIP1*, *RAD51C*, and *RAD51D*.

2. Mutations in *RAD51C* and *PALB2* were significantly associated with ovarian cancer.

3. The percentage of patients with risk-increasing gene mutations varies among cancers.

https://www.facingourrisk.org/XRAY/genetics-of-different-cancer-types
19% of ovarian cancer patients in this study had an inherited mutation in a gene that increases cancer risk, compared to only 4% of acute myeloid leukemia patients, indicating that inherited mutations play a greater role in ovarian cancer than acute myeloid leukemia.

11% of stomach cancer patients in this study carried an inherited mutation.

Limitations:
Researchers did not have information on the family histories of the cancer patients in this study, which would have provided more insight regarding the cancer risk conferred by the patients’ mutations. While the study looked at a sizeable group of patients, only a small number of them had some of the individual cancers. For example, only 178 prostate cancer patients were identified, compared to 770 breast cancer patients, which makes it difficult to draw conclusions about prostate cancer from the limited sample size. Additionally, because the majority of the study population was Caucasian, the results are more relevant to that population, and not as relevant to individuals of other backgrounds.

Conclusions:
It is important to remember that this single study does not prove that inherited mutations in some of these genes are directly associated with specific cancers. According to the study authors, “This study is the largest to date that has integrated somatic and germline alterations to identify important genes across 12 major types contributing to cancer susceptibility, and our results provide a promising list of candidate genes for definitive association and functional analysis.” This means that the researchers found many new genes to study, but more work needs to be done before their data becomes clinically relevant. People with mutations in one of the genes highlighted in this study should talk to their health care providers about their cancer risk and how to manage it.

Posted 03/01/16

SEARCH XRAY STUDIES AND ARTICLES

Keyword:

Cancer Type:
Choose

Relevant for:
Choose Cancer Type First...

Categories:
Categories: ○AND - ○OR

☐ - Alternative Treatments
☐ - Basic Science
☐ - Cancer Diagnosis
☐ - Cancer Risk
☐ - Cancer Treatment

https://www.facingourrisk.org/XRAY/genetics-of-different-cancer-types
Study: Do women who eat a high fiber diet have a lower risk of breast cancer?

SUMMARY

Some researchers believe that dietary fiber may decrease breast cancer risk by lowering estrogen levels in the blood. However, many previous studies have failed to find a link between fiber consumption and lower breast cancer risk. The current study suggests that consuming high dietary fiber during adolescence and young adulthood may lower breast cancer risk, but more work needs to be done to confirm this finding. In the meantime, everyone is encouraged to eat a variety of high fiber foods for the many well-documented health benefits. (03/08/16)

This article is relevant for:

- Adolescent and young adult women

This article is also relevant for:

- Preivors
- Women under 45
- Healthy people with average cancer risk
Researchers think that eating a high-fiber diet may reduce breast cancer risk by reducing estrogen levels in the body.

**Study findings:**

1. A high-fiber diet during early adulthood (ages 27-44) was associated with lower risk of breast cancer.
2. A high-fiber diet during adolescence was also associated with lower risk of breast cancer.

**What does this mean for me?**

This study indicates that eating dietary fiber during adolescence and early adulthood may reduce breast cancer risk. More research needs to be done to confirm this finding, because previous studies, which looked at fiber consumption in older women, do not agree with this finding.

Regardless of its effect on breast cancer risk, incorporating fiber into the diet benefits a healthy lifestyle. The American Cancer Society guidelines recommend eating foods that are high in fiber. The Mayo Clinic notes that a diet high in fiber maintains bowel health, lowers cholesterol levels, controls blood sugar levels and helps people to achieve and/or maintain a healthy weight.

Posted 3/18/16

Share your thoughts on this XRAYS article by taking our brief survey.

**References**


Mayo Clinic Staff. "Dietary fiber: Essential for a healthy diet."

**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

The American Cancer Society (ACS) guidelines on exercise, nutrition and weight for cancer prevention recommend the following:

**Diet and nutrition**

- Follow a healthy eating pattern, which includes:
WHO COVERED THIS STUDY?

NPR
A diet high in fiber may help protect against breast cancer ★★★★★☆

CBS News
Teen eating habits may help cut breast cancer risk ★★★★★☆

Huffington Post
High-fiber diet may help lower breast cancer risk ★★★★★☆

Glamour
Reason 283 to have a salad for lunch today: Fiber Is shown to lower your breast cancer risk ★★★★★☆

Health Day
Girls who eat more fiber may face lower breast cancer risk later: Study ★★★★★☆☆

Teen Vogue
This Is what you need to eat as a teen to help prevent breast cancer ★★★★★☆☆

How we rated the media

IN-DEPTH (click to expand)

IN DEPTH REVIEW OF RESEARCH

Study background:
Previous research found that dietary fiber does not affect breast cancer risk. However, most of these studies involved older women, and did not look at fiber consumption during adolescence or early adulthood, a critical time when exposure to factors that affect estrogen levels may affect breast cancer risk.

In March 2016, Maryam Farvid and colleagues from the Harvard T.H. Chan School of Public Health and other institutions published a paper in the journal Pediatrics that examined the relationship between dietary fiber intake during adolescence and young adulthood and breast cancer risk later in life.

Researchers of this study wanted to know:
Whether dietary fiber can modify breast cancer risk.

Population(s) looked at in the study:
This study involved 90,534 premenopausal women between the ages of 27-44 who were part of the Nurses’ Health Study II cohort. To be a part of this study, the women could not have reported a previous cancer diagnosis (except non-melanoma skin cancer). The women answered questionnaires that asked about their diet from the point the study began, and were resurveyed every four years over a 20-year period.

This group of women was also asked to complete another questionnaire about their diet during high school; 47,355 women returned this questionnaire.

**Study findings:**

1. Consuming dietary fiber during early adulthood reduced breast cancer risk. Women who consumed the most fiber (about 25 grams per day) reduced their breast cancer risk the most compared to women who consumed the least fiber (less than 13 grams per day). The women who consumed the most fiber reduced their risk of getting breast cancer by 19%.

2. Consuming both soluble fiber (found in peas, beans and apples) and insoluble fiber (found in nuts and wheat bran) reduced breast cancer risk. Women who consumed high dietary soluble fiber had a 14% reduction in breast cancer risk, while women who consumed high dietary insoluble fiber had a 20% reduction in breast cancer risk.

3. Total dietary fiber intake during adolescence was associated with a lower risk of breast cancer. Women who consumed the most fiber during adolescence had a 16% reduction in breast cancer risk.

**Limitations:**

High-fiber foods also contain many other biologically active ingredients—researchers noted that they cannot exclude the possibility that some ingredients other than fiber contributed to lower breast cancer risk. Additionally, the study population was not a random sampling of women in the U.S.; all participants were registered nurses who are a part of the Nurses’ Health Study II cohort. All studies that look at these types of associations may be affected by other factors that researchers were unable to identify or control. The researchers in this study took into account many other factors that could affect breast cancer risk, but they were unable to definitively say that no other factors were involved.

**Conclusions:**

This study suggests that consuming a diet that is high in fiber during adolescence and early adulthood may reduce breast cancer risk. However, more work needs to be done to confirm this finding. In the meantime, people should be sure to include dietary fiber in their diets regardless of the effect on breast cancer risk, as it is part of a healthy lifestyle.
Study: Prenatal exposure to the pesticide DDT and breast cancer risk

SUMMARY

This study found an association between prenatal exposure to the pesticide DDT, and an increased risk of women developing breast cancer. While this study does not prove that DDT exposure directly causes breast cancer, it serves as a reminder that pregnant women’s exposure to toxic environmental agents can affect their children’s risk for disease later in life.

This article is relevant for:
- Women with prenatal exposure to DDT, women in countries where DDT is used
- Previvors
- Women under 45
- Women over 45
- Healthy people with average cancer risk

STUDY AT A GLANCE

This study is about:
The relationship between pregnant women’s exposure to DDT, a widely-used pesticide in the U.S. during the 1960s, and breast cancer risk in their daughters.

Why is this study important?
Previous research found that females who were exposed to the manufactured estrogen DES while in the womb grew to become women with increased risk of breast cancer. No prior research was conducted to determine whether prenatal exposure to a similar molecule, DDT, also increases breast cancer risk. Although still used in Africa and Asia, DDT was widely used in the U.S. during the 1960s; many women who were exposed in the womb before the pesticide was banned in 1972 are now about the age of heightened breast cancer risk.

**Key study findings:**

Women who had a high exposure to one form of DDT while in their mother’s womb had an almost 4 times the increased risk of developing breast cancer by age 52.

**What does this mean for me?**

This study shows a link between high DDT exposure in the womb and a person’s risk of developing breast cancer by age 52. More research is needed to confirm this finding and understand how DDT might increase risk. Women who know they were exposed to DDT while pregnant should talk to their children about a potential increased risk of breast cancer, to make sure their children stay up to date on breast cancer screenings.

Posted 9/15/15

**References**


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**Questions to Ask Your Doctor**

- I might have been exposed to ________ while pregnant/before pregnancy. Will this affect my child? If it might, what should my child do?
- I might have been exposed to ________. How will this affect me? What should I do?
WHO COVERED THIS STUDY?

Reuters
In Utero DDT exposure tied to increased breast cancer risk

Public Radio International
Pre-natal exposure to DDT linked to increased likelihood of breast cancer

Forbes
Prenatal DDT exposure In 1960s linked to more aggressive breast cancer

Fox News
Prenatal DDT exposure linked with four times the risk of breast cancer

How we rated the media

IN-DEPTH (click to expand)

RESEARCH SUMMARY

Study background:
Previous research found no link between midlife DDT exposure and breast cancer. However, a link may still exist—exposure to DDT might only be significant when exposed at a certain age or period in a person’s life. It’s important for scientists to study this association, because although banned in the United States, DDT is still widely used as a pesticide in Africa and Asia. In the United States, many women who were exposed to DDT during its widespread use in the 1960s are alive today and could be at increased risk for breast cancer.

Researchers of this study wanted to know:
Whether a mother’s exposure to DDT affected breast cancer risk in their female children.

Population(s) looked at in the study:
Participants in this study belonged to a well-studied group known as the Child Health and Development Studies Pregnancy Cohort, which was specifically designed to study the associations between prenatal exposures and health and development in parents and their children. The women gave blood samples throughout their pregnancies, which occurred between 1959-1967. Researchers continued to follow the 9,300 female births up to the age of 54. Of these women, 137 were diagnosed with breast cancer by the age of 52. To study the relationship between DDT and breast cancer, researchers compared DDT levels in the blood from the pregnant mothers of 137 women who were diagnosed with breast cancer to DDT levels in the blood from the pregnant mothers of 315 women without breast cancer who were matched in age (these women were the control group).

Study results:
Women who had high prenatal exposure of DDT had:

- an almost 4 times increased risk of developing breast cancer by age 52.
- a greater than 4 times increased risk of developing HER2-positive breast cancer by age 52.
- a greater than 4 times increased risk of developing a more advanced cancer by age 52.

The study had limitations. Because the entire study population was from Oakland, California, the results may not apply to people from other regions. Researchers cannot definitively conclude that prenatal exposure to DDT was the single factor that accounted for increased risk in the women with breast cancer, or if additional exposure after birth also affected breast cancer risk. Nor could researchers conclude that DDT was the only agent that was present prenatally and resulted in increased cancer risk in these women—exposure to other environmental pathogens or pesticides may have also played a role.

Also, this study only noted whether women were diagnosed with breast cancer by age 52. It did not mention at what ages the women developed cancer, so we do not know if early-onset cancer was involved. And this study only included women from the general population; it is not known how DDT affects people with mutations in BRCA or other genes that predispose people to develop breast cancer.

**Conclusion:**

Because DDT is still used in the world in accordance with World Health Organization guidelines, its effect on people is important to study. This research does show a potential link between high exposure to DDT in mothers and increased breast cancer risk in daughters; however, more work is needed to confirm this finding in a larger, more diverse population, and to determine additional information, including how DDT increases cancer risk, and whether other pesticides have similar effects.

A FORCE advisory board member noted that knowing which women from the 1960s were exposed to DDT in the womb would be difficult if not impossible, so it would also be difficult to use these findings for the benefit of this group of women.

Women concerned with prenatal exposures and breast cancer risk should remember that DDT is only one of several agents that are linked to increased breast cancer risk, including:

- polycyclic aromatic hydrocarbons (PAHs, a type of air pollutant)
- bisphenol A (BPA, used in the production of plastics)
- tobacco smoke

**SEARCH XRAY STUDIES AND ARTICLES**

Keyword:  
Cancer Type:  
Choose  

Relevant for:  
Choose Cancer Type First...
Study: BRCA mutations more common than expected in young black women with breast cancer

SUMMARY

Most estimates of the percentage of breast cancer patients with mutations in BRCA are based on studies in White women. These researchers found that Black women diagnosed at a young age with breast cancer were twice as likely to have a BRCA mutation than previously reported based on studies in White women with breast cancer diagnosed in the same age categories. This study shows how important it is for all Black women diagnosed with breast cancer before age 50 to speak with their doctor about genetic counseling and testing. (9/29/15)
Why is this study important?

Genetic testing can provide women with breast cancer with important information that may affect their medical decisions. Genetic testing can also provide clues about the risk for cancer in relatives. This study is the largest in the United States to look at how common BRCA mutations are in Black women diagnosed with breast cancer at the age of 50 or younger, regardless of family history of breast and/or ovarian cancer.

Study finding(s):

1. Twelve percent of Black women diagnosed at age 50 or younger with invasive breast cancer had a BRCA mutation.
2. Of the Black women who tested positive for a BRCA mutation, 40% did not have a family history of breast or ovarian cancer.
3. BRCA mutations were found in 30% of the Black women diagnosed at age 50 or younger with triple negative breast cancer.
4. BRCA mutations were found in 22% of Black women diagnosed with breast cancer at 35 years of age or younger. Women with BRCA1 mutations were often diagnosed at a younger age than other women in the study; this trend was not found for women with BRCA2 mutations.

Limitations

Because the study was conducted with only young Black women in Florida and race was self-reported, this study may not be able to be generalized to young Black women in other states. Because family history is not collected by the Florida cancer registry, we have no way to know if family history influenced participation.

National Guidelines

National guidelines recommend that any woman diagnosed with breast cancer before age 50 be referred for genetic counseling and testing.

What do these findings mean for me?

If you are a Black women diagnosed at 50 years of age or younger with invasive breast cancer, you should ask your doctor about referral for genetic counseling and testing for an inherited mutation. Genetic counseling and testing is recommended even for women with no family history of cancer.

posted 9/29/15

Share your thoughts on this XRAYS article by taking our brief survey.

References:


https://www.facingourrisk.org/XRAY/mutations-in-young-black-women
The National Comprehensive Cancer Network has guidelines on who should undergo genetic counseling and testing. If you have been diagnosed with breast cancer, you should speak with a genetics expert about genetic testing if any of the following apply to you:

- You have a blood relative who has tested positive for an inherited mutation
- You have any of the following:
  - Breast cancer at age 50 or younger
  - Male breast cancer at any age
  - Ovarian cancer at any age
  - Triple-negative breast cancer at any age
  - Two separate breast cancer diagnoses
  - Eastern European Jewish ancestry and breast cancer at any age
  - Metastatic breast cancer
  - Testing of your tumor shows a mutation in a gene that is associated with hereditary cancer
  - HER2-negative breast cancer and high risk for recurrence
  - Lobular breast cancer and a family history of diffuse gastric cancer

OR

- You have one or more close family members who have had:
  - Young-onset or rare cancers
  - Breast cancer at age 50 or younger
  - Triple-negative breast cancer
  - Male breast cancer, ovarian cancer, pancreatic cancer, or metastatic prostate cancer at any age
  - Two separate cancer diagnoses
  - Prostate cancer at age 55 or younger or metastatic prostate cancer

The American Society of Breast Cancer Surgeons (ASBrS) released guidelines in 2019 that recommend all women diagnosed with breast cancer have access to genetic testing for inherited mutations in breast cancer genes.
**IN DEPTH**

**Study background:**
There has been very little research in the past that examined how many Black women with breast cancer have BRCA mutations. Most previous studies have focused on BRCA testing in non-Hispanic White women. These studies estimated that about 5% of all breast cancer patients have a BRCA mutation. Only three prior studies have looked at population-based BRCA testing in Black women in the United States, and those studies did not look for all known mutations in BRCA1 and BRCA2. This population-based study included Black women diagnosed with breast cancer at 50 years of age and under, regardless of their family history of cancer. All women were recruited to the study through the Florida Cancer Registry. All women who consented to the study received full gene sequencing and comprehensive rearrangement testing of the BRCA genes at no cost.

**Researchers of this study wanted to know:**
What the prevalence of BRCA mutations was in Black women diagnosed with invasive breast cancer at a younger age.

**Population(s) looked at in the study:**
396 Black women who were diagnosed with invasive breast cancer at 50 years or younger and completed BRCA testing following study consent.

**Study results:**
- About 12% of Black women diagnosed at age 50 or younger with invasive breast cancer (49/396) had a BRCA mutation.
- A BRCA mutation was present in 30% of the Black women diagnosed with triple-negative breast cancer at age 50 or younger.
- About 50% of BRCA mutation carriers had triple-negative breast cancer compared to about 20% of non-BRCA mutation carriers.
About 40% of Black women diagnosed at a young age with invasive breast cancer and found to have a BRCA mutation (20/49) had no first degree relative (parent, sibling, child) and/or second degree relative (grandparent, grandchild, aunt/uncle, niece/nephew) with breast and/or ovarian cancer.

The BRCA mutation prevalence for Black women diagnosed with invasive breast cancer at 35 years old or younger was 22%.

Seven percent of Black women between the ages of 46 and 50 who were diagnosed with invasive breast cancer that was not triple-negative had a BRCA mutation.

Limitations

Because the study was conducted with only young Black women in Florida and race was self-reported, this study may not be able to be generalized to young Black women in other states. Because family history is not collected by the Florida cancer registry, we have no way to know if family history influenced participation.

Conclusion:

Because of the higher frequency of BRCA mutations reported in this and other studies, BRCA testing for young Black women diagnosed at a young age with invasive breast cancer is appropriate. As this study found that about 40% of women with a known BRCA mutation did not have a close family history of breast and/or ovarian cancer, a personal history of breast cancer diagnosed at a young age regardless of family history is an indicator for BRCA testing in young Black women.
Study: Are more men with breast cancer opting for prophylactic mastectomy?

SUMMARY

Recent headlines describe the rise in prophylactic double mastectomy for men with breast cancer. We looked at the research to see how many men are choosing this option and what it means for men with breast cancer. (10/6/15)

AT A GLANCE

This study is about:

What are the factors that lead men with breast cancer in one breast to choose to undergo double mastectomy.

Why is this study important?

Researchers have seen the rates of double mastectomy increase in women with breast cancer but they do not know if this increase is also true for men.

Study findings:

This article is relevant for:

- Men diagnosed with breast cancer

This article is also relevant for:

- Men with breast cancer

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https://www.facingourrisk.org/XRAY/men-with-breast-cancer
1. The rate of prophylactic mastectomy doubled (from 3% to 6%), but the overall number is still very small, with only 106 of 1884 men with invasive cancer in one breast choosing to undergo double mastectomy.

2. The factors associated with a higher likelihood of double mastectomy include: younger age, white race, and having private insurance rather than Medicaid.

**What does this mean for me?**

This study indicates an increase in the rate of men choosing double mastectomy between 2004-2005 and 2010-2011. However, it is important to note that most men with breast cancer have a unilateral mastectomy (approximately 75% of men in 2004-2005 and 2010-2011 chose this option). The decision to undergo a single or double mastectomy should be a personal, individual one, made in consultation with your healthcare provider.

Posted 10/6/15

Share your thoughts on this XRAYS article by taking our brief survey.

**References:**


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
WHO COVERED THIS STUDY?

**Newsweek**
*Rise Seen in Preventive Mastectomy for Male Breast Cancer Patients* ★★★★★

**CNN**
*Double Mastectomies for Men with Breast Cancer on the Rise* ★★★★★

**ABC News**
*More Men With Breast Cancer Opting for Double Mastectomies* ★★★★★

**Medical Daily**
*The Angelina Jolie Effect: Prophylactic Surgeries Nearly Double in Men With Breast Cancer* ★★★★★

**The Market Business**
*Double Mastectomy is an Answer for Most Male Breast Cancer Patients* ★★★★★

How we rated the media

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**IN DEPTH (click to expand)**

**IN DEPTH**

**Study background:**
Researchers have noted increased rates of double mastectomy in women diagnosed with invasive cancer in one breast. This trend is especially true for younger women. Factors that researchers believe contribute to the increased rates of double mastectomy include:

- increased BRCA() testing
- use of MRI() (some research suggests MRI findings cause patients to worry about cancer developing in the opposite breast)
- the desire to achieve symmetry through reconstructive surgery

Although more women are opting to undergo double mastectomy – which comes with a risk of complications and costs – studies have not shown a survival benefit from the surgery. Unlike women, the double mastectomy rates among men with cancer in one breast and the various factors that contribute to their decisions are unknown.

**Researchers of this study wanted to know:**

Whether the double mastectomy rate in men has increased.

**Population(s) looked at in the study:**
6332 men who:
- Were at least 20 years old
- Had been diagnosed with stage I-III invasive breast cancer in one breast
- Underwent surgery between 2004 and 2011

**Study finding(s):**

1. Comparing the double mastectomy rates during 2004-2005 to 2010-2011 indicates that the rate of this surgery increased from 3% to approximately 6%.
   - 35 of 1166 men with invasive cancer in one breast chose to undergo double mastectomy in 2004-2005 while 106 of 1884 men with invasive cancer in one breast chose to undergo double mastectomy in 2010-2011

2. The factors that were associated with a higher likelihood of double mastectomy were:
   - younger age
   - white race
   - having private insurance rather than Medicaid

**Limitations:**
The researchers note that studies have found that increased BRCA testing has increased prophylactic mastectomy rates in women with breast cancer. This research was not able to look at the BRCA status of those in the study population. However, because male breast cancer is linked to BRCA1, BRCA2 and other inherited mutations, it is possible that a sizable number of study participants may have been found to be mutation carriers.

**Discussion:**
According to study author Dr. Ahmedin Jemal, quoted in a Newsweek article, “it’s important for male patients to ask a physician about their individual risk for contralateral breast cancer before making any decisions about the surgery...It’s only the patients at high risk who are likely to benefit from the procedure.”

Although not as much research has been done on men with breast cancer, we do know that those with a BRCA2 mutation have a 7% risk of developing breast cancer by age 70. No studies, however, look at the risk of a second breast cancer diagnosis in men with BRCA2 mutations. By looking only at male survival rates and failing to also look at recurrence rates, researchers are unable to consider the possibility that double mastectomy may be decreasing the occurrence of a second cancer, helping these patients avoid further treatment.

In women without a BRCA mutation, the chance of a second breast cancer diagnosis 10 years after the initial diagnosis is approximately 10%. The risk is 10%-30% for breast cancer survivors with a BRCA mutation.

Additionally, it is important to note that the researchers were able to see a significant difference in the rate of double mastectomy only between the years 2004-2005 and 2010-2011. They were unable to see any significant differences when comparing rates in 2004-2005 to those in 2006-2007 or in 2008-2009. Although the lack of a rate increase between 2006 and 2009 may strengthen the researchers’ argument that the increased rate of double mastectomy is, in fact, new, more data needs to be collected to ensure the trend is stable rather than something unique to 2010 and 2011.

**Conclusions:**
For both men and women, the decision to undergo a prophylactic mastectomy should be an individual, personal one, made by patients in consultation with their healthcare providers. Although the data from this study indicate the rates of this surgery in men with breast cancer have increased, more research is needed, both to understand why the rates have increased and to determine if there is a subset of men who will benefit from the procedure.
Study: New research may lead to a blood test that detects breast cancer recurrence earlier

SUMMARY

Recent headlines announced a blood test that can potentially predict which breast cancer survivors are at risk of recurrence. This particular blood test, one of many being developed, is sometimes called a "liquid biopsy." This early research focuses on a technique that is promising, but not yet available to breast cancer survivors. (10/12/15)

Note: THIS INFORMATION HAS BEEN UPDATED on 11/07/19 with newly-published data. See our updated article: A new blood test may help predict early-stage breast cancer patients at highest risk for recurrence.
Read the article that we reviewed

AT A GLANCE

Note: THIS INFORMATION HAS BEEN UPDATED on 11/07/19 with newly-published data. See our updated article: A new blood test may help predict early-stage breast cancer patients at highest risk for recurrence.

This study is about:
Early research on a new blood test, sometimes called a liquid biopsy, that may help identify patients who are at risk of breast cancer recurrence.

Why is this study important?
With an effective method of identifying patients who are at risk of recurrence, clinical trials of therapies aimed to prevent relapse could be targeted towards these patients.

Study findings:
1. The blood test that looks for tumor DNA could accurately predict metastatic recurrence.
2. 96% of patients who did not relapse had no detectable tumor DNA in their blood.

What does this mean for me?
This small study is still early in the development process. While results are promising, more work is needed before this test can be used to identify patients who are at risk of recurrence.

This article is relevant for:

- People diagnosed with early stage breast cancer
- Breast cancer survivors
- Women under 45
- Women over 45
- Men with breast cancer
- Triple negative breast cancer
- ER/PR +
- Her2+ breast cancer

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Questions to Ask Your Doctor

- Are there other ways to predict whether my cancer might recur?
- What signs and symptoms should I look for if I am concerned about my cancer recurring?
- What type of follow up care should I have after treatment to look for cancer recurrence?
WHO COVERED THIS STUDY?

CTV News

Blood test could predict breast cancer’s return: Study ★★★★★☆

The Guardian

Blood test may help predict breast cancer relapse ★★★★★☆

NBC News

Scientists work on new ‘Liquid Biopsy’ for breast cancer ★★★★★☆

Medical News Today

Breast cancer relapse could be predicted with new blood test ★★★★★☆☆

The Hoops News

Blood test can predict relapse in early breast cancer by tracking mutation in circulating tumor DNA ★★★☆☆☆

How we rated the media

IN DEPTH (click to expand)

IN DEPTH

Study background:
About 95% of women diagnosed with breast cancer have early-stage breast cancer with no evidence of metastasis. However, some of these women have micrometastatic disease, a form of metastasis in which breast cancer cells have spread, but newly formed tumors are too small to be detected by current imaging and testing technologies. Treatment and surgery do not always eliminate these micrometastatic lesions, and currently, we are unable to determine which patients still have micrometastatic disease (also called minimal residual disease—MRD) and which do not. Circulating tumor DNA (ctDNA) is released into the blood by dying tumor cells. ctDNA are small pieces of tumor DNA that characterize the genetic features of tumors in patients with advanced cancer. However, little data is available regarding detection of ctDNA in early-stage breast cancers to predict if they are likely to recur.

Researchers of this study wanted to know:
Whether looking for circulating tumor DNA (ctDNA) in the blood can identify patients with micrometastatic disease.
Population(s) looked at in the study:
The study followed 55 early-stage breast cancer patients for about 2 years.

- None of the patients had metastatic disease at diagnosis that was detectable by standard methods.
- All of the patients received chemotherapy followed by surgery (i.e. neoadjuvant) therapy.

Study findings:
1. 15 of the 55 study patients (27%) relapsed.
2. The amount of circulating tumor DNA (ctDNA) present before treatment was not associated with early cancer recurrence.
3. In about half of patients who recurred (6 of 12 patients tested), ctDNA was detected in a blood sample taken 2-4 weeks after surgery. Sequential blood samples taken after the post-surgery sample found ctDNA in 12 of 15 patients (80%).
4. 96% of patients who did not relapse had no detectable tumor DNA in their blood.
5. Patients who were found to have ctDNA had a median of 7.9 months before their relapse could be detected clinically.
6. ctDNA detection predicted relapse in all the major breast cancer subtypes (ER-positive breast cancer, ER-negative breast cancer, HER2+ breast cancer, and triple-negative breast cancer).
7. Brain metastasis in 3 patients was not detected by ctDNA.
8. ctDNA was more similar to the relapsed tumors than the original tumor.

Limitations:
While results from this study population are promising, the sample size of 55 patients is relatively small. Because the study only looked at patients who had surgery and chemotherapy, whether these findings apply to patients who have surgery only (without adjuvant chemotherapy), or to patients who have surgery followed by adjuvant chemotherapy is unknown. Additionally, the follow-up period was short—about 2 years for most patients—so whether other patients recurred after the follow-up period is also unknown.

Conclusions:
In this study, ctDNA was found a median of 7.9 months before the patient’s recurrence was detected in a clinic, indicating that identification of circulating tumor DNA (ctDNA) may be a potentially useful blood test to predict cancer relapse. The blood test could help physicians identify patients for clinical trials to prevent relapse, because ctDNA would be identified several months before a relapse could be detected clinically. However, because of the limited sample size and specified treatments of the study population, it is unclear whether or not these results will apply to everyone with breast cancer. But it is very promising, and more work should be done to pursue ctDNA and other liquid biopsy tests to detect cancer recurrence.

References:

Posted 10/12/15

https://www.facingourrisk.org/XRAY/blood-test-for-breast-cancer-relapse
Study: Impact of familial breast cancer risk on young girls

SUMMARY

Does growing up in a family that is at high risk for breast cancer affect young girls? Recent research found girls from families with BRCA mutations and/or a strong family history of cancer to be as well adjusted as peers of the same age. The one difference was that girls from families facing breast cancer risk had more stress related to breast cancer than their peers. While these findings are reassuring, parents know their children best, and they should ask for help if they believe their daughters are not coping well. (11/03/2015)

STUDY AT A GLANCE

This study is about:

How young girls are impacted by growing up in families with a history of breast cancer and/or BRCA mutations.

Why is this study important?

This article is relevant for:

- Young women and girls from high-risk breast cancer families

This article is also relevant for:

- Previvors
- People with a genetic mutation linked to cancer risk
- Breast cancer survivors
- Women under 45
As the use of genetic testing has become more available, people are more aware of their elevated cancer risk due to a BRCA or other gene mutation. Because parents who are mutation carriers have a 50% chance of passing their mutation and its high risk onto their children, it is important to study and understand how children in high-risk families respond, cope and perceive their own breast cancer risk.

**Study findings:**

1. Young girls within families with a history of breast cancer or a BRCA mutation reported higher breast cancer-specific distress than young girls from families without a family history of breast cancer.

2. A girl’s amount of distress was found to be directly affected by the amount of distress exhibited by her mother with breast cancer: as a mother’s breast cancer-specific distress increased, so did her daughter’s.

3. Girls from families with a history of breast cancer or BRCA mutation did not have worse general psychosocial adjustment than their peers.

**What does this mean for me?**

While young girls from familial breast cancer families do not have worse general psychosocial adjustments than their peers, they do experience more breast cancer-specific distress. Parents know their children best; they should openly dialogue with their daughters, and ask for help if they believe their daughters are not coping well.

Published 11/03/15

Share your thoughts on this X-rays article by taking our brief survey.

**References**


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All X-Rays articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.
The following organizations have resources related to communicating with relatives about cancer risk.

- **FORCE related resources:**
  - Brochure: The Genes Between Us
  - Information: Sharing with Family
  - Information: Sharing Information with Adult Relatives
  - Information: Sharing Information with Children
  - Portal: Family History and Genealogy
  - Booklet: Talking about BRCA in your family tree
  - Video: Sharing Information with Children (from 2021 conference)
  - Blog: Let’s Talk About It
  - Blog: Do Not Wait: Empowering Other Families by Sharing My Story

- **CDC:**
  - Talking About Your Family History of Cancer | Bring Your Brave
  - Let’s Talk: Sharing Info About Your Family Cancer Risk (kognito.com)

Updated: 01/28/2022

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**WHO COVERED THIS STUDY?**

**CBS News**

*Are the kids all right? When breast cancer runs in the family.* ★★★★★★☆

**Examiner.com**

*Family history of breast cancer worries preteen girls about their risk* ★★★★★☆☆

**PsychCentral.com**

*Strong family breast cancer history does not hike anxiety in teens* ★★★★★☆☆

**How we rated the media**

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**IN-DEPTH (click to expand)**

**IN DEPTH REVIEW OF RESEARCH**

**Study background:**

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https://www.facingourrisk.org/XRAY/risk-and-young-girls
While previous studies looked at children’s response to having parents with cancer, few have studied how being from a family with a genetic or familial risk for breast cancer impacts children. Although results from studies of children with parents who have cancer suggest that these children may be at risk for internalizing and externalizing problems and general distress, the studies were often small and did not include a comparison group. It is important to understand how children are coping because research has shown that psychosocial distress can be associated with greater risk behaviors, such as alcohol and tobacco use. In this study, Dr. Angela Bradbury and colleagues at the University of Pennsylvania and the Children’s Hospital of Philadelphia looked at signs of distress in girls who were from families at high risk for breast cancer.

Researchers of this study wanted to know:

Do young girls with a family history of breast cancer or BRCA mutation have worse psychosocial adjustment (internalizing and externalizing problems and breast cancer-specific stress), higher risk taking, and lower preventive health behaviors than young girls without a familial breast cancer risk?

What factors are associated with higher perceived risk of breast cancer?

Population(s) looked at in the study:

The study included 869 mother-daughter pairs (441 pairs were from families with a history of breast cancer, while 428 were not). Daughters ranged from ages 6 to 13. Participants were from 5 U.S. study sites in these states: New York City, Philadelphia, Salt Lake City, the San Francisco Bay Area, and Canada (Ontario). Among the 441 mothers in the group with family history of breast cancer:

- about 40% had a personal history of breast cancer.
- about 14% had BRCA mutations.

The researchers assessed information that was gathered from surveying the mothers in each pair. Girls who were age 10 and older also self-reported information, while girls who were under age 10 did not.

The criteria for participating mothers and daughters with familial breast cancer risk was defined as having more than 1 close first- or second-degree relative (parent, child, sibling, grandparent, aunt or uncle) with breast cancer or a BRCA mutation. The comparison group did not have a family history of breast cancer or a BRCA mutation.

Study findings:

1. The more relatives who had breast cancer, the higher young girls perceived their risk.
2. Higher general anxiety in daughters was associated with higher anxiety in their mothers, in addition to poor family communication.
3. Girls from a family with familial risk were more likely to report that they had increased risk for breast cancer.
4. Girls in both groups (those with and without familial risk for breast cancer), were unsure of their exact risk.

Limitations:

This study only looked at mother-daughter pairs: there was no data on daughters with a deceased mother. Nor did the study take into account the impact of fathers. The study population of BRCA families was small.

Conclusions:

Being aware of how breast cancer impacts daughters in families with familial breast cancer risk is important. This study shows that daughters from these families are generally well adjusted, although they do have greater breast cancer-specific distress and anxiety, and perceive higher breast cancer risk. Being aware of this can help health care providers determine interventions to address concerns of both mother and daughter. Members of our advisory board will continue to review new research and provide useful information and resources for women who are at risk of breast cancer.
board also note that although the children in this study did not necessarily feel more distress than their peers, parents should remember that every daughter and every family is unique. Parents should be alert for any changes in a child’s typical behavior, such as sleep changes, worry, and/or a drop in school grades. It is important for parents to monitor their daughters’ behavior, open dialogue with them, and get help if they believe their daughter is not coping well.

Published 11/03/15

(back to top)
Study: Weight gain associated with breast cancer survivorship

SUMMARY

Weight gain in breast cancer survivors can affect survival and quality-of-life. This study found that breast cancer survivors are more likely to gain weight than women of the same age who are at high risk, but have never been diagnosed with cancer. The study looked at which groups of survivors were more likely to gain weight. (8/24/15)

This article is relevant for:
- Women diagnosed with early stage (1-3) breast cancer

This article is also relevant for:
- Men with breast cancer
- Triple negative breast cancer
- ER/PR +
- People with a genetic mutation linked to cancer risk
- Breast cancer survivors

https://www.facingourrisk.org/XRAY/weight-gain-associated-with-breast-cancer-survivorship
Weight gain is associated with various health issues. Weight gain is a risk factor for postmenopausal breast cancer. Among breast cancer survivors, higher Body Mass Index (BMI) and weight gain increases risk for breast cancer recurrence and/or a new primary cancer. This study compared weight gain between previvors (women at increased risk of breast cancer) and breast cancer survivors and looked specifically at women with a family history of breast cancer.

**Study findings:**

- Overall, breast cancer survivors gained about 3 pounds more weight than previvors.
- Women who received chemotherapy were twice as likely to gain at least 11 pounds at the researchers’ follow-up point compared with women who were never diagnosed with cancer.
- ER-negative breast cancer survivors had the greatest weight gain. This group gained on average approximately 7 more pounds than previvors.
- On average, premenopausal survivors gained more weight than postmenopausal survivors.

**What does this mean for me?**

This study shows that in women with a family history of cancer a breast cancer diagnosis and treatment is linked to weight gain. This study did not look at specific causes of, or ways to manage this weight gain. However, there are expert guidelines and programs available to help cancer survivors control their weight. Knowing your risk for weight gain after diagnosis and treatment may help you and your doctor create a plan for weight management after treatment.

posted 8/24/15

Share your thoughts on this XRAYS article by taking our brief survey.

**References**


**Disclosure**

FORCE receives funding from industry sponsors, including companies that manufacture cancer drugs, tests and devices. All XRAYS articles are written independently of any sponsor and are reviewed by members of our Scientific Advisory Board prior to publication to assure scientific integrity.

WHO COVERED THIS STUDY?

NBC News
Breast cancer survivors gain more weight, study finds ★★★★★☆☆

HealthDay
Breast cancer survivors tend to gain weight: study ★★★★★☆☆

Newsmax Health
Breast cancer survivors prone to weight gain: Johns Hopkins study ★★★★★☆☆

Time
Why breast cancer survivors gain more weight ★★★★★☆☆

How we rated the media

IN-DEPTH REVIEW OF RESEARCH

Study background:
Many studies have noted weight gain in breast cancer survivors, but they do not directly compare these women with women who have never been diagnosed with cancer. Without the comparison, it is harder to see whether breast cancer survivors are actually gaining more weight or not.

Researchers of this study wanted to know:
Whether breast cancer survivors with a family history of breast cancer gain more weight after their diagnosis compared to previvors.

Population(s) used in the study:
The study compared 303 breast cancer survivors with 307 previvors who had not had breast cancer. All women had either a family history of breast or ovarian cancer, a BRCA1/2 mutation, or a diagnosis of early breast cancer (diagnosed at age 40 or younger). Participating breast cancer survivors had a personal history of breast cancer (DCIS (3) or stage I-III breast cancer) that had been treated with surgery. The previvors included in the study were matched to the survivors based on age and menopausal status. The breast cancer survivors in this study were further subdivided into two categories: survivors who had been diagnosed with breast cancer 5 years or less prior to the study start date, and survivors who had been diagnosed with breast cancer more than 5 years prior to the study start date.

Study results:
- Overall, breast cancer survivors gained on average approximately 3 more pounds than previvors.
- When compared with other subtypes, breast cancer survivors who were diagnosed with ER-negative invasive breast cancer within the 5 years prior to the study start date had the greatest weight gain. This group gained on
average approximately 7 more pounds than previvors.

- Premenopausal breast cancer survivors diagnosed with breast cancer within the 5 years prior to the study start date gained on average approximately 6 more pounds than premenopausal previvors.
- Postmenopausal breast cancer survivors diagnosed with breast cancer within the 5 years prior to the study start date gained on average approximately 4 more pounds than postmenopausal previvors.
- Overall, breast cancer survivors who had received chemotherapy with or without hormone therapy gained on average approximately 4 pounds compared to previvors. An average weight gain of approximately 8 pounds was seen in breast cancer survivors treated with chemotherapy only.
- Compared to previvors, survivors who received chemotherapy were 2.1 times more likely to gain at least 11 pounds at the researchers’ follow-up point.

Limitations

The majority of the study population was white, which means that these findings might not apply to breast cancer survivors of other racial or ethnic backgrounds. Researchers also did not directly measure the women’s weights—they relied on self-reporting, which may not have been accurate. Additionally, breast cancer survivors who did not have a family history of cancer were not included in the comparisons.

Conclusion:

This is a highly relevant study for breast cancer survivors. It shows that in women with a family history of breast cancer and/or a mutation in a gene that increases cancer risk, breast cancer survivorship is a risk factor for weight gain. However, it is important to remember that this is only an association—the study does not show that the weight gain is caused by the breast cancer or the chemotherapy used to treat the breast cancer. More research is needed to find the exact cause, but the study’s authors note that the chemotherapy associated weight gain might be due to less physical activity or with changes in the patient’s metabolism.

It is also important to note that the average overall weight gain in this study was approximately 3 pounds in breast cancer survivors. Currently we do not know whether gaining that amount increases risk of second primary cancer development or cancer recurrence. For comparison, a study done by Dr. Michelle Holmes’ research group found that women who gained between 0.5 and 2.0 kg/m² (average weight gain of approximately 7 pounds) and women who gained more than 2.0 kg/m² (average weight gain of approximately 20 pounds) had elevated risk of breast cancer death compared to women who maintained their weight.

In summary, there is an association between breast cancer and weight gain, and potential health problems are associated with weight gain. Researchers do not know the exact effect that gaining 3 pounds will have on breast cancer survivors. American Cancer Society guidelines say women should try to maintain their weight after a breast cancer diagnosis.

Share your thoughts on this XRAYs article by taking our brief survey.

posted 8/24/15

SEARCH XRAY STUDIES AND ARTICLES

Keyword:  |  Cancer Type:

https://www.facingourrisk.org/XRAY/weight-gain-associated-with-breast-cancer-survivorship
WHO COVERED THIS STUDY?

New York Times
Decades of data fail to resolve debate on treating tiny breast lesions

New York Times:
Doubt Is raised over value of surgery for breast lesion at earliest stage

The San Diego Union Tribune
Study challenges status quo in breast cancer treatment

USA Today
Study sparks debate on treatment for early stage breast cancer

News Medical
Low rate of mortality from breast cancer after DCIS diagnosis

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
Although DCIS cells are abnormal, they are not the same as invasive cancer cells. Unlike invasive cancer, DCIS lacks the ability to metastasize (spread to other areas of the body). Scientists long believed that untreated DCIS cells could turn into invasive cancer, which might then spread to other parts of the body and cause death. For this reason, DCIS lesions are generally removed and the remaining breast is treated with radiation to kill off any lingering cancer cells. However, data from previous studies and this more recent study show that even left untreated, DCIS seldom leads to death, and that removing DCIS does not help most women live longer. This study was done to learn which risk factors are associated with breast cancer mortality after a DCIS diagnosis.

Researchers of this study wanted to know:
How many women previously diagnosed with DCIS eventually die from breast cancer, and which women are at greatest risk for breast cancer death after DCIS.

Population(s) looked at in the study:
Data from approximately 108,000 women who were diagnosed with DCIS from 1988-2011 were obtained from the National Cancer Institute’s SEER () (Surveillance, Epidemiology and End Results) database. SEER collects information on all patients diagnosed with cancer, including the site of the primary cancer; the stage() of cancer at diagnosis, the first course of treatment; specific markers, such as HER2(), ER, and PR; and patient survival. Research using databases such as SEER is useful in designing controlled studies that compare how different treatment options affect survival.
Study results:

- 20 years after DCIS diagnosis, the breast cancer mortality rate was approximately 3% for all women.
- Women who were diagnosed with DCIS before age 35 had the highest risk of death from breast cancer after 20 years. The 20-year risk was still low (approximately 8%).
- Women who were diagnosed with DCIS between ages 35-39 had a 4.5% risk of developing invasive breast cancer after 20 years.
- On average, women who were diagnosed with DCIS between ages 40 and 69 had an approximate 3% risk of developing invasive breast cancer after 20 years.
- African American women had a 7% risk of death at 20 years after DCIS diagnosis, compared to 3% for white, non-Hispanic women.
- Radiotherapy after lumpectomy reduced the risk of developing an invasive recurrent breast cancer from about 5% to 2.5%. However, this reduction did not translate to a reduction in risk of death from breast cancer.
- Of the 956 women who died of breast cancer (out of 108,196 women total) after their DCIS diagnosis, most (approximately 55% of the 956 women) did not have a record of invasive in-breast recurrence.

Limitations:

Researchers were unable to tell which cases of DCIS were detected through screening and which cases were symptomatic. The researchers did not have access to information that could affect risk of recurrence and/or second primary breast cancer such as:

- tamoxifen use after DCIS
- body mass index
- family history of breast cancer
- the presence of mutations in \( \text{BRCA} \) or other genes associated with increased cancer risk
- whether or not the later invasive cancer was a recurrence of the original cancer or a new breast cancer in the same or opposite breast

Conclusion:

This study highlights two populations who have a higher risk of breast cancer mortality after DCIS diagnosis: young women (under 40) and African American women. As breast surgeon Dr. Laura Esserman said in an editorial that was published on this study, "For young women (<40 years) who present with symptomatic DCIS—approximately 5% of the population—we should be cognizant that this is a different disease than typical DCIS." Esserman noted that new tests that look at a patient’s tumor can help health care providers identify which patients with DCIS could benefit from more aggressive treatment.

This study did not look at patients’ BRCA status or their family history of breast cancer. While the study shows that the risk of dying from breast cancer after a DCIS diagnosis is generally low, young women and African American women should be monitored more regularly and more thoroughly. Women diagnosed with DCIS before the age of 50 meet national guidelines for referral to genetic services; they may wish to discuss the possibility of genetic counseling and/or testing with their health care provider.

Experts note that this study alone does not mean that doctors should stop treating women with DCIS; rather, it is an indicator for further discussion and research on how to best treat DCIS in different populations.
WHO COVERED THIS STUDY?

Health Day
More young breast cancer patients getting gene test ★★★★★

Reuters
More young breast cancer patients having genetic tests ★★★★★

Medical Daily
Genetic testing for BRCA breast cancer gene on the rise in young women; does it even influence treatment decisions? ★★★★★

Oncology Nurse Advisor
Genetic testing for BRCA gene mutations increasing among younger women with breast cancer ★★★★

DailyMail.com
The 'Angelina effect' IS real: More women under 40 are having genetic testing for the deadly BRCA gene ★★★

US News
Health buzz: More young women with breast cancer genes seeking testing, study finds ★★★★

How we rated the media

IN DEPTH REVIEW OF RESEARCH

Study background:
For a young breast cancer survivor, knowing that you have a BRCA mutation alerts you to increased risk for both a second breast cancer and ovarian cancer. BRCA mutation carriers have a variety of treatment and cancer risk management options, including risk-reducing mastectomy, removal of the ovaries and fallopian tubes, risk-reducing medication, increased screening, and eligibility for clinical trials that study new targeted therapies. However, previous research has shown that although all young women with breast cancer meet guidelines for BRCA testing, many are still not being offered the opportunity to test.
In February 2016, Dr. Ann Partridge and colleagues from the Dana-Farber Cancer Institute and other institutions published a paper in JAMA Oncology about their study of BRCA mutation testing in young women with breast cancer.

**Researchers of this study wanted to know:**
How BRCA testing is utilized in young women and whether this genetic information or knowledge about genetic risk affects their choice of treatment.

**Population(s) looked at in the study:**
A total of 897 women who were diagnosed with breast cancer at age 40 or younger participated. The women, who are part of the Helping Ourselves, Helping Others: The Young Women’s Breast Cancer Study cohort, are patients from community hospitals in Massachusetts and academic sites in Massachusetts, Denver, Colorado, Rochester, Minnesota, and Toronto.

**Study findings:**
1. 87% of young women who were diagnosed with breast cancer reported having BRCA testing within one year after their diagnosis.
2. The number of women age 40 or younger with breast cancer who had genetic testing increased from about 77% in August 2006 to about 96% in December 2013.
3. About 96% of young women who were diagnosed with breast cancer during both 2012 and 2013 received BRCA testing.
4. About 30% of young women diagnosed with breast cancer said that genetic information or concern about cancer risk made a difference when they were making decisions regarding treatment.
   - About 86% of BRCA mutation carriers chose bilateral mastectomy, compared to 51% of women who did not carry a BRCA mutation.
5. Among young women who did not have BRCA testing, about 69% said that a health care provider had talked to them about the possibility of having a BRCA mutation.
   - Of those who did not discuss BRCA testing with their healthcare provider:
     - 19% said they were planning on discussing this in the future
     - 22% said they were thinking about discussing it in the future
     - 30% said they did not know if they wanted to discuss this in the future
     - 14% said they were not interested in talking about BRCA.
   - Researchers asked why women did not have genetic testing and found that:
     - 24% didn’t think they were at risk for having a mutation
     - 24% didn’t get tested because their health care provider thought it was unlikely that they had a mutation
     - 18% of women did not get testing because they were worried about insurance or work issues that might occur if they received a positive test result
     - 11% did not get testing because they could not afford it.

**Limitations:**
This study was performed when genetic testing for hereditary risk of breast cancer was limited primarily to BRCA1 and BRCA2 gene analysis. At the time, Myriad Genetics Inc., held a patent on BRCA testing, which was struck down by the Supreme Court in 2013. Now, many young breast cancer survivors are offered expanded panel testing that simultaneously analyzes several novel hereditary breast cancer genes, including BRCA. The genetic testing landscape is rapidly changing, and more work is needed to evaluate the use of multigene panels for young breast cancer survivors. For example, it is possible that some of the BRCA-negative women in this study could harbor a mutation in one of the hereditary breast cancer genes included on the panel tests, and would carry other cancer risks that would have influenced their management decisions.

Additionally, these findings are limited to young women who are likely insured, and the majority was treated in academic cancer centers. It is possible that women in areas without access to experts in cancer genetics are not getting testing as often as the women in this study. In an editorial in the same issue of JAMA Oncology, Dr. Kathleen Blazer and colleagues wrote, "We concur with the authors that, unfortunately, it is unlikely that this level of access to, or participation in [genetic cancer risk assessment] would be found in the community setting or among the economically underserved or ethnic minorities."

**Conclusions:**

The study authors noted, “Our findings highlight recent trends, experiences, and perspectives surrounding BRCA testing in women diagnosed as having breast cancer at 40 years and younger.” This study indicates that BRCA testing is increasing in young women with breast cancer. More work needs to be done to evaluate the use of multigene panels in both the young breast cancer survivor as well as other at risk populations. The editorial by Dr. Blazer and colleagues also noted that, “The task remains to ensure that the benefits of [genetic cancer risk assessment] reach more individuals and families, including those among underrepresented minorities, with economic disparities, and in low-to-middle-income countries.”

Share your thoughts on this XRAYS article by taking our brief survey.

Posted 3/22/16

**SEARCH XRAY STUDIES AND ARTICLES**

**Keyword:**

**Cancer Type:**

- Choose

**Relevant for:**

- Choose Cancer Type First...