Development and Evaluation of a Decision Aid on Mammography Screening for Women 75+

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2004-2005 Individual National Research Service Award, 1 F32 CA110424- Mammography Screening Decisions in Elderly Women

2006-2008 Hartford Geriatrics Health Outcomes Research Scholars Award
Breast Cancer Screening, Characteristics, and Outcomes Among Oldest-Old

2007-2009 K23 from the NIA, 1 K23 AG028584, Benefits and Burdens of Screening Oldest-Old Women: The Case of Mammography

2007-2009 T. Franklin Williams Scholars Award in Geriatrics, Society of General Internal Medicine / Association of Chiefs of General Internal Medicine / Association of Specialty Professors: The Psychological Impact and Decision-Making of Older Women after an Abnormal Mammogram

2009-2013 K23/Paul B. Beeson Career Development Award in Aging K23
Benefits and Burdens of Screening Oldest-old Women: The Case of Mammography

2013-2016 NIH/NIA R01AG041869 Breast Cancer Risk Factors Among Women Aged 75 and Older

2014-2018 NIH/NCI R01CA181357 Randomized Trial of a Mammography Decision Aid for Women Aged 75 and Older
Overview

• Women 75+ years are the fastest growing segment of the US population

• Breast cancer incidence increases with age

• Mammography reduces breast cancer mortality by 15 to 25% for women 50 to 74
Overview

• None of the mammography randomized controlled trials included women 75+

• 56% are regularly screened with mammography
  – 50% of women with <10 year life expectancy

• Harms
  – pain; anxiety; biopsy complications, and overdiagnosis
  – 97% of US women >65 undergo surgery for early stage breast cancer
Overdiagnosis among women 75+

- Breast cancer may be particularly burdensome to older women
  - comorbidity, frailty, less access to medical information, declining social networks, more experience with loss
  - Increase side effects from treatment
- Overdiagnosis likely increases with age due to decreased life expectancy, slower growing tumors
  - Ductal carcinoma in situ (DCIS) likely represents overdiagnosis in women 75+
Policy

• USPSTF state that there is insufficient evidence to recommend mammography screening for women 75+ years.

• SGIM/AGS choosing wisely campaign recommend not screening women with <10 year life expectancy

• All groups recommend older women be informed of the pros and cons before being screened

• However, few are adequately informed; many overestimate benefits and underestimate risks
Aim

• To develop and pilot test a decision aid (DA) for women 75+ years to inform their decision-making and help them make more preference sensitive decisions around mammography screening
Development of the DA

- International DA standards

- Decision-making processes/literacy of older adults

- Pamphlet format:
  1) low computer/internet literacy of women 75+
  2) paper-based DAs have been shown to have equivalent effects on behaviors and associated with greater satisfaction and use
  3) community physicians tend to prefer to give pamphlets
Should I Continue Getting Mammograms after age 75?

This is a tool to help you make this decision. You will need a pen/pencil to complete parts of this tool.
What is the purpose of this tool?

- Doctors do not know if mammograms benefit women age 75 or older.

- This tool will help you think about whether or not you want to stop or continue getting mammograms.

- This tool is NOT for women who have had breast cancer or who have breast pain or symptoms.

Breast cancer risk factors among women aged 75+

- The chance of getting breast cancer goes up with age. Women age 75 and older have a higher chance of getting breast cancer than younger women. But breast cancers often grow slower in older women.

- A family history of breast cancer slightly increases the chance that a woman age 75 or older will get breast cancer.

- Having had a breast biopsy (tissue removed from the breast) slightly increases the chance that a woman age 75 or older will get breast cancer.
Why do women get mammograms?

- Women get mammograms to find breast cancer early before it causes problems.
- Mammograms do not keep you from getting breast cancer.
- Mammograms do not find every breast cancer.
- Experts think that a small breast cancer found on an older woman’s mammogram would not have caused problems for at least 5 or 10 years. Some of the cancers may never have caused problems.

Am I in good enough health to get a mammogram?

On average a 75 year old woman will live to age 88 (13 more years)
On average an 80 year old woman will live to age 90 (10 more years)
On average an 85 year old woman will live to age 92 (7 more years)
On average a 90 year old woman will live to age 95 (5 more years)

The graph below shows on average how many more years women live at different ages.
Your health also influences whether you can benefit from getting a mammogram. Answer the questions below to learn more about your health.

Answer the 10 questions below and add up your points from both pages to learn more about your health.

1. How old are you?
   - 75 – 79: 0 points
   - 80 – 84: 2 points
   - 85+: 4 points
   - write your points here-------------------------→
   - Points:

2. How much do you weigh?
   - If more than 130 pounds: 0 points
   - If 130 pounds or less: 2 points
   - write your points here-------------------------→
   - Points:

3. Would you say your health is:
   - Excellent (0 points)
   - Very Good (0 points)
   - Good (1 point)
   - Fair (2 points)
   - Poor (2 points)
   - →
   - Points:

4. Have you ever been told by a doctor or health professional that you had emphysema or chronic bronchitis or COPD?
   - No (0 points)
   - Yes (2 points)
   - write your points here-------------------------→
   - Points:

5. Have you ever been told by a doctor or health professional that you had a cancer? (do not include skin cancer unless it was melanoma)
   - No (0 points)
   - Yes (2 points)
   - write your points here-------------------------→
   - Points:

6. Have you ever been told by a doctor or health professional that you had diabetes? (including borderline or pre-diabetes)
   - No (0 points)
   - Yes (2 points)
   - write your points here-------------------------→
   - Points:

Total from this page

Continue on next page
7. Because of a physical, mental or emotional problem, do you need help from other people with routine needs? These include everyday household chores, shopping or getting around for other purposes?

   No (0 points)  Yes (2 points)  write your points here------------------------→

8. By yourself and without using any special equipment, how difficult is it for you to walk a quarter of a mile (about 3 city blocks)?

   Not at all difficult (0 points)
   A little difficult to very difficult (3 points)
   Can’t do at all/do not do/can only do with a cane or walker (3 points)→

9. Which best describes your cigarette use?

   Never smoked or smoked less than 100 cigarettes in your life (0 points)
   Former smoker (1 point)
   Current smoker (3 points)→

10. During the past 12 months, how many times were you hospitalized overnight?

    None (0 points)
    Once (1 point)
    Twice or more (3 points)  write your points here------------------------→

   Now add up all of your points from questions 1-10 from BOTH pages:

   ________

   Circle your score below to learn what it means:

   0 1 2 3 4 5 6 7 8 9 10 11 or more

   A mammogram may help you live longer
   A mammogram is unlikely to help you live longer
   A mammogram is very unlikely to help you live longer
What happens to 1,000 women age 75 or older who **CONTINUE** or **DO NOT** get mammograms over 5 years
-Each circle represents 1 woman out of 1,000-

Women like you who **CONTINUE** to get mammograms

1000 women-

750-

500-

250-

0-

**100 False Alarms** – These women have an abnormal mammogram but additional tests do not show breast cancer. Some women find this experience causes anxiety.

Additional tests include:

- Additional Mammograms
- Breast Ultrasounds
- Breast Biopsies
What happens to 1,000 women age 75 or older who CONTINUE or DO NOT get mammograms over 5 years

Women like you who CONTINUE to get mammograms

1000 women-

750-

500-

250-

0-

- 4 are diagnosed with a pre-cancer
- 20 are diagnosed with early stage breast cancer: cancer confined to the breast
- 2 are diagnosed with late stage breast cancer: cancer that spread outside the breast
- 974 are not diagnosed with breast cancer

Women like you who DO NOT get mammograms

1000 women-

750-

500-

250-

0-

- 0 are diagnosed with pre-cancer
- 12 are diagnosed with early stage breast cancer: cancer confined to the breast
- 4 are diagnosed with late stage breast cancer: cancer that spread outside the breast
- 984 are not diagnosed with breast cancer

**Summary:** Women who get mammograms are more likely to be diagnosed with pre-cancers and early stage breast cancers. Some of these cancers would not have caused problems in their lifetimes.

-Two more women out of 1,000 who do not get a mammogram are diagnosed with late stage breast cancer.
Below is approximately the number of women age 75 or older out of 1,000 that will die of breast cancer in the next 5 years

- Doctors are unsure that getting a mammogram will lower your chances of dying from breast cancer, some studies suggest the numbers below:

**Women like you who **CONTINUE** to get mammograms**

1000 women-

750-

500-

250-

0-

- **3 out of 1,000** women die of breast cancer

**Women like you who **DO NOT** get mammograms**

1000 women-

750-

500-

250-

0-

- **4 out of 1,000** women die of breast cancer

**Summary:** Out of 1000 women 1 less woman may die of breast cancer who chooses to get a mammogram
Below are the causes of death among women age 75 and older who die in the next 5 years.

- Many more women age 75 and older die of heart disease than breast cancer.
Below are treatments offered to women with breast cancer. It is important to think about whether you would be willing to be treated before getting a mammogram.

**Surgery:**

- **Breast-Conserving Surgery (lumpectomy):** Only the lump of breast cancer is removed from the breast. Most older women do well after this surgery.
- **Mastectomy:** Surgical removal of the breast. Some older women experience pain, infection, swelling in their arm, and even death after mastectomy.

**Pills:** Hormonal therapy pills are generally taken for 5 years to prevent breast cancer from coming back. These pills may cause hot flashes, bone pain, osteoporosis, or fatigue in some women.

**Radiation Therapy:** The use of high-energy radiation to get rid of cancer cells. Radiation usually requires transportation to a medical center 5 days a week for several weeks. Radiation may cause fatigue and breast pain.

**Chemotherapy:** An intravenous (IV) medication that is given weekly to get rid of cancer cells. These drugs can have side effects like vomiting, fatigue, diarrhea, or infections. Few women age 75 or older are treated with chemotherapy.
Below are some of the pros and cons of getting a mammogram. Check ✓ the points that are important to you when deciding whether or not to get a mammogram. Add more check marks ✓ if a point is more important to you than other points.

**Pros** to getting a mammogram

1. A mammogram is more likely to find breast cancer when it is small, improving my chances of only needing a minor surgery.

2. Getting a mammogram may lower my chances of dying from breast cancer, but this is not certain.

3. Getting a mammogram may help me feel good about myself and my health.

**Cons** to getting a mammogram

1. A mammogram may find a breast cancer that would never have caused problems or symptoms in my lifetime.

2. Getting a mammogram may increase the number of tests (additional mammograms, ultrasounds, and breast biopsies) or treatments (surgeries, radiation, chemotherapy, pills) that I get. Some of these tests or treatments can harm older women.

3. Getting a mammogram may be uncomfortable or make me feel anxious.

**Other Pros that Matter to You**

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

**Other Cons that Matter to You**

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
In the next year are you going to get a mammogram?

Please place a check mark \( \checkmark \) in one of the boxes below:

If you are sure you want a mammogram, check the box far to the LEFT. If you are sure you do NOT want a mammogram, check the box far to the RIGHT. If you are unsure, check a box somewhere in between.

In the next year:

I Will Get a Mammogram  I am Undecided  I Will NOT Get a Mammogram

Now, you may want to talk about what you have learned from this tool with your doctor.

*The numbers presented in this booklet are the best available from the medical literature. Last updated: 9/2013.
Pretest/Posttest Trial (Pilot)

- Eligible
  - Women 75-89 years
  - English-speaking
  - No history of dementia
  - No history of invasive/non-invasive breast cancer
  - Not screened in the past 9 months
  - Screened in the past 3 years
  - Not documented that she has stopped mammos
  - Not first visit with PCP
Study Flow

1. Complete “Before” Survey
2. Read the Decision Aid
3. PCP visit
4. Complete “After” Survey
5. Medical record review for follow-up
Outcomes

- Knowledge of pros/cons of mammography (10 items)
- Decisional conflict (16 items)
- Screening intentions (15 point scale categorized yes/no/undecided)
- Documented discussion of the pros/cons of screening in the 5 years before/6 months after the intervention
- Receipt of screening 15 months after (at least 2 years since last mammogram)
Analyses

• We used the signed rank and McNemar’s test to compare pretest/posttest responses

• In subset analyses, examined the effect of the decision aid by life expectancy (<10 years, ≥10 years)
Sample Population (n=45)

- Median age: 79 years (range 75-86)
- 69% were Non-Hispanic white
- 60% had attended some college
- 58% had <10 year life expectancy
- Patients from 25 different PCPs
  - 15 of the PCPs completed a questionnaire about using the decision aid
# Results (n=45)

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<thead>
<tr>
<th></th>
<th>Before</th>
<th>After</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>6.3 (+/-1.3)</td>
<td>7.3 (+/-1.4)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Decisional conflict</td>
<td>20 (+/-14)</td>
<td>17 (+/-12)</td>
<td>0.10</td>
</tr>
<tr>
<td>Intend: yes</td>
<td>82%</td>
<td>56%</td>
<td>0.004</td>
</tr>
<tr>
<td>&lt;10 year life expectancy</td>
<td>85%</td>
<td>50%</td>
<td>0.004</td>
</tr>
<tr>
<td>≥10 year life expectancy</td>
<td>79%</td>
<td>63%</td>
<td>0.45</td>
</tr>
</tbody>
</table>
## Results (n=45)

<table>
<thead>
<tr>
<th></th>
<th>Before</th>
<th>After</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documented discussion</td>
<td>11% (up to 5 years before)</td>
<td>53% (6 months after)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Underwent screening</td>
<td>84% in 2 years before</td>
<td>63% in 15 months after</td>
<td>0.02</td>
</tr>
<tr>
<td>&lt;10 year life expectancy</td>
<td>80%</td>
<td>52%</td>
<td>0.04</td>
</tr>
<tr>
<td>≥10 year life expectancy</td>
<td>89%</td>
<td>78%</td>
<td>0.63</td>
</tr>
</tbody>
</table>
Additional Results (n=45)

- 93% found the DA helpful
- 96% would recommend the DA
- 76% found the amount of information just right (22% too much information)
- 42% found the information balanced, 42% slanted towards not getting a mammogram, 16% slanted toward getting a mammogram
- 98% prefer educational materials to be on paper
PCP results (n=15)

• 73% agreed that using the DA would allow their patients to make more informed decisions

• 80% agreed that the DA would help their patients make more value-laden decisions

• 93% thought it would be helpful to patients

• 87% thought the amount of information was right but 67% thought it was too long

• 67% found it balanced while 33% found it slanted toward not getting a mammogram
Limitations

- Limited generalizability - one site, small study, highly educated sample

- Quasi-experimental design:
  - Results could be due to temporal (improvement in knowledge scores) or secular changes (decreased screening)

- Could not separate effect of PCP vs effect of DA
Conclusions/Next steps

• Our before/after trial suggests that the decision aid helps older women make more informed, preference-sensitive decisions around mammography screening

• We are currently testing this DA in a large cluster randomized controlled trial in Boston and North Carolina (R01 CA181357)
Future Directions

• How to disseminate broadly and integrate into primary care

• Need for a web-based tool that can be integrated into EHRs

• Tailored risk information

• Discussing life expectancy with patients
Thank you!