Cervical and Breast Cancer Screening for Women with Developmental Disabilities

Susan Parish, Karen Luken, Jamie G. Swaine, Esther Son

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“Cascade of disparities” for people with developmental disabilities (Krahn et al.)

Emerging evidence: Health promotion for people with disabilities is critical yet often ignored (Rimmer et al.)

Established commitments to self-determination for people with disabilities
  little evidence of implementation in health care
Background: Cervical & Breast Cancer Screening

- Cancer screening recommendations set by the US Preventive Health Services Task Force
- Cervical cancer, once the leading cause of cancer deaths among women, is now completely treatable and preventable with Papanicolaou smear test (Pap test)
- Breast cancer: 2nd most frequently diagnosed cancer & 2nd leading cause of cancer deaths in women
- Routine mammography reduces mortality by ~20%
- Changing guidelines
  - Mammography guidelines changed in 2009 (controversial)
  - Pap test guidelines changed in spring 2013
Background: Cervical & Breast Cancer Screening for U.S. Women with DD

- Existing research suggests women with developmental disabilities have among the worst rates of cervical and breast cancer screening in the United States.
  - Limitations: Self-reported or proxy-reported data
- Barriers to care
  - Women’s limited knowledge
  - Fear surrounding procedures
  - Physicians’ pejorative attitudes
- No evidence-based interventions have been established as effective in increasing women’s receipt of screening
- Our focus: Empowering women to be informed, assertive patients
Goal 1: Identify cervical & breast cancer screening determinants & rates

- Existing estimates of screening rates derived from self-reported or proxy-reported interview data
  - Biased reporting is highly likely by all women regardless of their disability status
  - Accuracy is unclear: women more accurate about if they received screening versus when they received screening
  - Accuracy of reporting by women with developmental disabilities has not been studied

- Obtained screening data from medical practices
  - Extraction forms: dates of Pap test, mammography, clinical breast exam, physical exam, insurance type
  - 91% response rate from 253 medical practices
  - Item non-response 6-9% for each procedure in last year
Participants’ counties of residence in North Carolina, US

= Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor

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## Description of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 203 women</th>
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<tbody>
<tr>
<td>Race is Black</td>
<td>47%</td>
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<tr>
<td>Race is Asian, Native or Latina</td>
<td>3%</td>
</tr>
<tr>
<td>Has a child</td>
<td>13%</td>
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<tr>
<td>Lives alone or with partner</td>
<td>8%</td>
</tr>
<tr>
<td>Lives in formal residential setting</td>
<td>40%</td>
</tr>
<tr>
<td>Lives with family caregiver</td>
<td>45%</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>40 years (19 - 71 years range)</td>
</tr>
<tr>
<td>Impairment is mild or moderate</td>
<td>91%</td>
</tr>
<tr>
<td>Lives in rural area</td>
<td>75%</td>
</tr>
<tr>
<td>Insured</td>
<td>&gt;99%</td>
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</tbody>
</table>
Percent of women receiving screening procedures, 2006-10

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Pap test receipt among NC women \( \geq 18 \) in 2008, 2009, or 2010

*North Carolina data from 2010 BRFSS*
Determinants of Cervical Cancer Screening

Women were more likely to receive cervical cancer screening if they:

- Lived in a residential facility (as opposed to at home with family caregiver)
- Lived in a rural area
- Received care from an OB/GYN

Parish et al (2013) *Public Health Reports*
Mammography receipt among NC women $\geq 40$ in 2009 or 2010

- **Women with ID**: 61%
- **Women without ID**: 77%

* North Carolina data from 2010 BRFSS

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Unadjusted mammography rates for Black & White women ages ≥40

In multivariable analyses, White women were 5x more likely to receive mammography than Black women.

Percent Receipt Rate

<table>
<thead>
<tr>
<th>Year</th>
<th>White</th>
<th>Black/African American</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>59</td>
<td>29</td>
</tr>
<tr>
<td>2008 or 2009</td>
<td>76</td>
<td>51</td>
</tr>
<tr>
<td>2008 and 2009</td>
<td>43</td>
<td>11</td>
</tr>
</tbody>
</table>

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Goal 2: Develop and test revised intervention to promote cervical and breast cancer screening

- Women Be Healthy 2
- Expansion of Women Be Healthy developed by Lunsky, Straiko, Armstrong; (revised by Havercamp, Dickens)
- In randomized control trial, Women Be Healthy 1 improved breast cancer screening knowledge of women with intellectual disabilities but not cervical cancer screening knowledge
- 3 focus groups with women with ID and 15 instructor interviews
- Women particularly uncomfortable with content related to cervical cancer

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**Women Be Healthy 2**

- WBH2 is 22-session (1 hour twice/weekly) psycho-educational program for women with intellectual and developmental disabilities
- All activities geared for learners without literacy
- Doubled content on pelvic exams, cervical cancer & screenings from 3 to 6 hours
- Expanded relaxation activities
- Curriculum is **FREE** and available on the Lurie Institute for Disability Policy website: http://lurie.brandeis.edu/women/curriculum.html
Women Be Healthy 2 content

- Anatomy using models and dolls
- Cancer
- Importance of cancer screenings
- Importance of healthy behaviors
- Communicate with health care provider
- Know what is normal for you
- Know when you need to visit the health care provider
- Relaxation exercises
- Field trips to GYN office & mammography site
- Multimedia, hands-on activities

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http://lurie.brandeis.edu/women/curriculum.html
Goal: Test Women Be Healthy 2

- Randomized control trial
- 21 sites across North Carolina
  - Community rehab programs
  - Community colleges
  - Other disability service provider organizations
- Pre-test, post-test interview design
  - Computer-assisted, in-person interviews
- Randomized sample at each site
- Curriculum taught by on-site instructors (not research team members)
- Compared WBH1, WBH2 to women in the control group
- 9 indicators of knowledge plus composite
Post-test Knowledge of Women with I/DD

Definition of cancer

Note: adjusted for baseline, living arrangement & site type

Mean Score

9 item composite

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Predicted Probabilities: Post-test Breast Cancer Knowledge

Predicted probabilities of correct response

Breast cancer knowledge indicator

What to do if you find a lump
Definition of mammogram
Frequency of mammogram
Whose job is it to do the breast exam

Control
WBH
WBH2

Note: adjusted for baseline, living arrangement & site type

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Post-test Cervical Cancer Knowledge of Women with I/DD

Cervical Cancer Knowledge Indicator

- Definition of Pap test
- Frequency of Pap test
- Pap test picture identification
- Identify ways to decrease anxiety for pelvic exam

Predicted probabilities of correct response

- Control
- WBH
- WBH2

Note: adjusted for baseline, living arrangement & site type

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Implications

➢ Women with developmental disabilities have low rates of cervical and breast cancer screening

➢ Women with developmental disabilities who live in the community have limited knowledge about cervical and breast cancer screening

➢ A targeted intervention, geared to learners with low literacy, can improve the knowledge about cervical and breast cancer screening of women with developmental disabilities

➢ Modest knowledge gains in breast cancer but not cervical cancer indicate greater duration of content related to cervical cancer is necessary

➢ Clear need for targeted intervention with women, caregivers, health care providers
Some Important Anecdotes

- Some women with ID were raped, sometimes by multiple perpetrators
- Some women had children (13% of the sample), sometimes with multiple partners
- Some women had HIV or HPV
- Many women were sexually active
- Many women were using birth control
- Several medical providers stated that the women did not need Pap tests because of their ID

- Two physicians wrote on medical record forms “not needed because mentally retarded” [sic]
Conclusions

- Women with intellectual and developmental disabilities do not receive cervical and breast cancer screening according to clinical guidelines.
- Assertive efforts are needed to ensure that Black women with intellectual and developmental disabilities receive mammography.
- Women with intellectual and developmental disabilities can benefit from a tailored intervention to improve their knowledge about these screenings.
- Women with ID who live in the community are at risk for developing HPV and cervical cancer and should receive Pap tests according to clinical guidelines.
Check us out on YouTube!

http://www.youtube.com/watch?v=jgTrbWUdclg
Thank you!

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For more info: [http://lurie.brandeis.edu/women/index.html](http://lurie.brandeis.edu/women/index.html)