Cervical & Breast Cancer Screening for Women with Intellectual Disabilities

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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 ~3 weeks ago
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
Background: *Women Be Healthy*

- Health promotion intervention designed to empower women with developmental disabilities to obtain cervical and breast cancer screening

- 90-minute psycho-educational classes, once/weekly
  - Eighth week is graduation (7 weeks of instruction)

- Content: anatomy, cancer, importance of screenings, communicating with health care providers, field trip to GYN office
Randomized Control Trial of *Women Be Healthy*

- Identification of screening barriers
  - Medical records
  - Family caregivers
- Development of recruitment & consent protocol
- Assessment of women’s accuracy in reporting procedures
- Feasibility & acceptability trial of WBH2
- Examine racial disparities in screening
- Develop WBH2
- Evaluation of intervention implementation fidelity
- Determine screening rates from medical records
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First Priority: Development of Inclusive Research Protocol

- People with developmental disabilities have historically been research subjects but not research partners
- Research team includes a woman with developmental disabilities
- Majority of Advisory Board is women with developmental disabilities
- Partnership: protocol developed collaboratively with women with developmental disabilities, prior to grant development
  - Recruiting procedures
  - Consent procedures
  - Interview procedures
  - Knowledge translation activities
- Extensive training of Advisory Board; commitment to collaboration
- Builds from Heller et al.
## Description of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 203 women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race is Black</td>
<td>47%</td>
</tr>
<tr>
<td>Race is Asian, Native or Latina</td>
<td>3%</td>
</tr>
<tr>
<td>Has a child</td>
<td>13%</td>
</tr>
<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>
</tr>
</tbody>
</table>
Participants’ counties of residence

= Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor
Determine Cervical & Breast Cancer Screening 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 whether they received screening than 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 analyzed
Percent of women receiving screening procedures, 2006-10

Percent of Receipt Rate

Pap Mamm (≥40)

2006 2007 2008 2009 2010

22 30 34 29 28

46 51 53 46 47
Percent of women receiving screening procedures, 2006-10

![Graph showing the percent of women receiving screening procedures from 2006 to 2010. The graph includes data for Pap, Mamm (≥40), and Physical procedures.]

Mammography receipt among women $\geq 40$ in 2009 or 2010 in NC

* North Carolina data from 2010 BRFSS
Pap test receipt among women ≥ 18 in 2008, 2009, or 2010 in NC

- Women with ID: 54%
- Women without ID: 84%

* North Carolina data from 2010 BRFSS
Unadjusted mammography rates for Black & White women ages ≥40

In multivariate analyses, White women were 6x more likely to receive mammography than Black women.
Testing *Women Be Healthy*

- Randomized control trial with wait-list controls
- 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)
- Post-test interviews mean of 13 days after intervention
## Knowledge at baseline and post-test (% correct)

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Control Baseline</th>
<th>Control Post-test</th>
<th>Experimental Baseline</th>
<th>Experimental Post-test</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Define cancer</td>
<td>39</td>
<td>42</td>
<td>32</td>
<td>39</td>
<td>NS</td>
</tr>
<tr>
<td>Define mammogram</td>
<td>45</td>
<td>48</td>
<td>41</td>
<td>55</td>
<td>2.33**</td>
</tr>
<tr>
<td>Mammogram frequency</td>
<td>22</td>
<td>21</td>
<td>15</td>
<td>29</td>
<td>3.09**</td>
</tr>
<tr>
<td>Who should do breast exam</td>
<td>90</td>
<td>89</td>
<td>90</td>
<td>91</td>
<td>NS</td>
</tr>
<tr>
<td>What should you do if find lump</td>
<td>71</td>
<td>81</td>
<td>70</td>
<td>72</td>
<td>NS</td>
</tr>
<tr>
<td>Define Pap test</td>
<td>38</td>
<td>52</td>
<td>40</td>
<td>51</td>
<td>NS</td>
</tr>
<tr>
<td>Frequency of Pap test</td>
<td>19</td>
<td>29</td>
<td>18</td>
<td>37</td>
<td>NS</td>
</tr>
<tr>
<td>Pap instrument identification</td>
<td>59</td>
<td>70</td>
<td>59</td>
<td>70</td>
<td>NS</td>
</tr>
<tr>
<td>Ways to reduce anxiety</td>
<td>41</td>
<td>48</td>
<td>43</td>
<td>58</td>
<td>NS</td>
</tr>
<tr>
<td>9-item composite (mean)</td>
<td>4.3</td>
<td>4.8</td>
<td>4.1</td>
<td>5.0</td>
<td>.38**</td>
</tr>
</tbody>
</table>

No statistically significant group differences at baseline; Odds Ratio represents significant regressions, controlling baseline knowledge; referent group is control group; red indicates significant knowledge gains within group.
RCT Conclusions?

- *Women Be Healthy* was modestly effective in increasing women’s knowledge about breast cancer screening
- Ineffective in increasing women’s cervical cancer knowledge
- Focus groups with women & instructor interviews
  - Women were uncomfortable with material related to cervical cancer
  - Inadequate instructional time spent on cervical cancer information
- Knowledge gains in the control group were interesting
  - Anecdotally, we heard from many women in the control group that they wanted to participate, diffusion of knowledge from the experimental group is possible; it is also possible that the interviews were a form of intervention
Some Noteworthy Anecdotes

- Women with developmental disabilities were often raped and/or had children, sometimes by multiple partners
- Increased risk for cervical cancer
- Some medical providers stated that the women did not need Pap tests because of their impairments
- Two wrote on medical record forms “not needed because mentally retarded” (sic)
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.
Knowledge Translation Process

- Trained Advisory Board on development of knowledge translation plan
  - Framework: Barwick & Lockett (2010) & Core Group’s *Designing for Behavioral Change*

- Advisory Board prioritized audiences and mechanisms
  - For women with disabilities & family caregivers
    - Website
    - YouTube, Facebook
    - Checklists for health care visits
  - For advocates: research briefs
  - For researchers
    - Peer-reviewed journal articles, research briefs
Website

The website includes separate sections for:

- **Women with Disabilities**
  - Doctor visit worksheet, health screenings guidelines, fact sheets, research guide for self-advocates, health checklists

- **Caregivers**
  - Communication tips, notes for social workers and case managers, health checklists

- **Health care professionals**
  - Accommodating patients with disabilities

- **Researchers**
  - Links to peer-reviewed journal articles, research briefs
  - Revised curriculum

http://lurie.brandeis.edu/women/index.html
Facebook

- Launched *Women Be Healthy* Facebook site early March

http://www.facebook.com/womenbehealthy

65 people like us!!!
YouTube

- Advisory Board prioritized this as an important way to reach women with disabilities
- Problem: Advisory Board more tech savvy than research team
  - The good news: they’re trying to bring us along
- Two YouTube videos have been developed

http://www.youtube.com/watch?v=jgTrbWUdclg
Next Steps

- Field testing *Women Be Healthy 2* in seven sites with ~40 women with developmental disabilities
- Preliminary evidence: women and instructors like the new content and it is feasible in this format
- Developing an intervention targeted for caregivers is critically important
- Family caregivers play major role in women’s access to care
- Multi-modal approach will be necessary
  - Workshops, health fairs, smart phone apps, website content, mailings, DVDs
- Test of the effectiveness of *Women Be Healthy 2* in increasing women’s receipt of cervical & breast cancer
- Expand knowledge translation activities

Lurie Institute for Disability Policy
Thank you!

- Participants, Advisory Board, community partner sites, instructors
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- Research team: Karen Luken, Jamie Swaine, Pam Dickens, Grace Wright, Glenna Williams, Esther Son, Sarah Dababnah, Rod Rose, Michelle Techler, Allison Ivie

For more info:
http://lurie.brandeis.edu/women/index.html