Preventive Health Care for Women with Developmental Disabilities

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Context

- “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 ~3 weeks ago
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
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

- Preliminary testing: women reported satisfaction

- Developers: Lunsky, Straiko, Armstrong; (revised by Havercamp, Dickens)
NIDRR Field-Initiated Research: Study & Sub-Studies

Randomized Control Trial of **Women Be Healthy**

- Evaluate intervention implementation fidelity
- Determine screening rates from medical records
- Develop recruitment & consent protocol
- Develop & test WBH2
- Examine racial disparities in screening
- Conduct feasibility & acceptability trial of WBH2
- Assess women’s accuracy in reporting procedures
- Identify screening barriers
  - Medical records
  - Family caregivers

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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
## 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>
Goal: 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

- Pap
- Mamm (≥40)
- Physical

2006: Pap 22, Mamm (≥40) 46, Physical 55
2007: Pap 30, Mamm (≥40) 51, Physical 52
2008: Pap 34, Mamm (≥40) 53, Physical 64
2009: Pap 29, Mamm (≥40) 46, Physical 61
2010: Pap 28, Mamm (≥40) 47, Physical 59

Percent of Receipt Rate

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

Women with ID

Women without ID

* North Carolina data from 2010 BRFSS

* Lurie Institute for Disability Policy
Unadjusted mammography rates for Black & White women ages ≥40

In multivariate analyses, White women were 5x more likely to receive mammography than Black women.
Pap test receipt among NC women ≥ 18 in 2008, 2009, or 2010

* North Carolina data from 2010 BRFSS

**Percent Receipt Rate**

- Women with ID: 54%
- Women without ID: 84%
Goal: Identify 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, forthcoming, *Public Health Reports*
Goal: Test *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; reference group is control group; red indicates significant knowledge gains within group.
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.

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Anecdotes & Conclusion

- 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 and/or on birth control
- Some 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]

- 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
Thank you!

- Participants, Advisory Board, community partner sites, instructors
- Funders: US Department of Education, NIDRR, Grant # H133G090124; NC Division of MH/DD/SAS, NC Office on Disability & Health; Lurie Institute for Disability Policy at Brandeis University
- 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