Changes in Reproductive Cancer Screening Knowledge of Women with Developmental Disabilities: Results from a Randomized Control Trial

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Background

- Women with developmental disabilities have among the worst rates of cervical and breast cancer screening in the United States
- Barriers to care
  - Women’s limited knowledge
  - Fear surrounding procedures
  - Physician’s pejorative attitudes
- Our focus: Empowering women to be informed, assertive patients
**Women Be Healthy intervention**

- Intervention designed to improve women’s knowledge and empowerment related to cervical and breast cancer screening
- Eight classes include hands-on experiential learning, field trip to GYN office, focus on empowerment AND knowledge
  - How to assert needs and ask questions with health care provider
  - How to describe symptoms
  - How to relax for stressful procedures (particularly pelvic exam)
  - Schedule of recommended procedures

*Women Be Healthy* used with ~500 women with intellectual disabilities
Satisfaction reported in initial pilot testing
Study Design

- Randomized control trial (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 interviews
- Randomized sample at each site
- Curriculum taught by on-site instructors who were not members of the research team (5 hrs of training provided)
- Interviewers did not know the status of the participants
- Post-test interviews mean of 13 days after intervention
### Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Control (n=84)</th>
<th>Experimental (n=91)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race is Black</td>
<td>45%</td>
<td>45%</td>
</tr>
<tr>
<td>Has a child</td>
<td>15%</td>
<td>13%</td>
</tr>
<tr>
<td>Lives alone or with partner</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>Lives in formal residential setting</td>
<td>49%</td>
<td>42%</td>
</tr>
<tr>
<td>Lives with family caregiver</td>
<td>43%</td>
<td>50%</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>41 years</td>
<td>40 years</td>
</tr>
</tbody>
</table>

No statistically significant differences between the groups on any measure
Indicators of Knowledge

- Definition of cancer
- Definition of mammogram
- Frequency of mammogram
- Whose job is it to do the breast exam
- What do you do when you find a lump?
- Definition of Pap test
- Frequency of Pap test
- Pap test instrument identification
- Identify ways to decrease anxiety for exams
- 9-item composite
Analysis

- Regression models
- Covariate: baseline knowledge
- Insufficient variance for controls of living arrangement, whether woman had child, marital status
### 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.
Implications

- 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
- 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 to the controls is possible; it is also possible that the interviews were a form of intervention
- Modest knowledge gains in breast cancer but not cervical cancer indicate greater duration of content related to cervical cancer is necessary
Thank you!

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