Cervical and Breast Cancer Screening of Women with Developmental Disabilities

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Background

- Women with developmental disabilities have among the worst rates of cervical and breast cancer screening in the United States
  - Self-reported or proxy-reported data
- 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
- Interviewers did not know the status of the participants
- Post-test interviews mean of 13 days after intervention
- Medical record data for receipt of screening
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
Rates of Receipt of Screening

CBE = Clinical breast exam
### Knowledge at baseline and post-test (% correct)

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

- 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 they were “mentally retarded” (sic)
- 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
Implications

- Women with developmental disabilities have exceptionally 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.
Thank you!

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