Cervical Cancer Screening for Women with Intellectual Disabilities

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for ONCODEFI
Background: Cervical Cancer Screening for U.S. Women with ID

- Existing research suggests women with intellectual disabilities have among the worst rates of cervical and breast cancer screening in the United States.
- We found 72% reduced likelihood of Pap test receipt for women with cognitive disabilities compared to other US women (Parish & Saville 2006).
- Limitations: Self-reported or proxy-reported data.
Aim: Identify objective cervical cancer screening rates & determinants

- Existing estimates of screening rates derived from self-reported or proxy-reported interview data
- Biased reporting is highly likely by all women
- Accuracy is unclear: women more accurate about *if* they received screening versus *when* they received screening
- Women with intellectual disabilities lack understanding of the exam and may be unable to accurately report receipt
- Caregivers may lack knowledge about the woman’s medical care
Procedure

- Physicians and medical practices obtained from the women, their staff, and/or family caregivers
- Obtained screening data from medical practices
  - Abstraction forms sought dates of Pap test, mammography, clinical breast exam, physical exam, insurance type for each year from 2006-10
  - 91% response rate from 253 medical practices
  - Item non-response 6-9% for each procedure in last year
- 1-10 faxed requests needed to obtain records
- Some facilities sent women’s entire medical records and not just the abstraction form
- Women (and guardians, as needed) previously provided informed consent and HIPAA consent
## Description of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 163 women</th>
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<tbody>
<tr>
<td>Race is Black</td>
<td>43%</td>
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<tr>
<td>Race is Asian, Native or Latina</td>
<td>3%</td>
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<tr>
<td>Has a child</td>
<td>14%</td>
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<tr>
<td>Lives alone or with partner</td>
<td>8%</td>
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<tr>
<td>Lives in formal residential setting</td>
<td>51%</td>
</tr>
<tr>
<td>Lives with family caregiver</td>
<td>41%</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>40 years (19 – 65 range)</td>
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<tr>
<td>Impairment is mild or moderate</td>
<td>92%</td>
</tr>
<tr>
<td>Lives in rural area</td>
<td>74%</td>
</tr>
<tr>
<td>Insured</td>
<td>&gt;99% (94% public)</td>
</tr>
<tr>
<td>Has legal guardian</td>
<td>36%</td>
</tr>
<tr>
<td>Unable to correctly define Pap test</td>
<td>64%</td>
</tr>
<tr>
<td>Someone accompanies woman into examination room</td>
<td>65%</td>
</tr>
</tbody>
</table>
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
Percent of women receiving screening procedures, 2006-10

![Graph showing the percent of women receiving screening procedures, 2006-2010. The graph includes data for Pap and Physical exams. The percent of receipt rates for Pap exams range from 22% in 2006 to 28% in 2010. The percent of receipt rates for Physical exams range from 55% in 2006 to 59% in 2010.](image-url)
Pap test receipt among NC women ≥ 18 in 2008, 2009, or 2010

Women with ID: 54%

Women without ID: 84%

* 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 (odds ratio [OR] = 1.79 compared to those living with family caregiver)
- Lived in a rural area (OR = 3.43 compared to those living in urban settings)
- Received care from an Obstetrician/Gynecologist (OR = 1.87 compared to those receiving care from generalist)
- Not associated with receipt of Pap: race, age, guardianship status, someone accompanies into exam room, impairment severity, knowledge of Pap test, insurance type, history of childbearing

Some Important Anecdotes

- Some women 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 intellectual disabilities

- Two physicians wrote on medical record forms “not needed because mentally retarded” *[sic]*
Do women with intellectual disabilities need cervical cancer screening?

- An estimated 68-83% of women with intellectual disabilities assaulted during lifetime, compared to 18% of nondisabled women (Tyiska; Tjaden & Thoennes)
- Women are unlikely to report their sexual histories to health care providers in the presence of a paid or family caregiver
- Caregivers are often the perpetrators of sexual assault, making reporting to health care providers even less likely
- Women lack knowledge about sexually transmitted diseases and often about anatomy
- Women’s fear of exams may lead to inaccurate reporting of sexual history

Yes!
Conclusions

- Women with intellectual disabilities do not receive cervical cancer screening according to clinical guidelines.
- Women with intellectual disabilities 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!

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- Research team: Karen Luken, Jamie Swaine, Pam Dickens, Grace Wright, Glenna Williams, Esther Son, Sarah Dababnah, Michelle Techler

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