Reproductive Cancer Treatment Hospitalizations of US Women with Intellectual and Developmental Disabilities

Leah Igdalsky, Susan L. Parish, Esther Son
Lurie Institute for Disability Policy
The Heller School for Social Policy and Management
Brandeis University, USA

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Overview

- Cancer among people with IDD
- Reproductive cancer among women with IDD
  - Protective Factors
  - Risk Factors
- The Data: Cancer Treatment Hospitalizations
- Unanswered Questions
Cancer Among People with IDD

- Cancer is second leading cause of death in the USA (CDC, 2015)
- The life expectancy of people with IDD has increased, they are now exposed to greater cancer risk
- Incidence of all cancers in people with IDD is not significantly different from the general population (Sullivan et al., 2004)
- Cancer is a major public health concern
Increased Risk of Certain Cancers

- There are some cancers that are more common among people with IDD
  - men with IDD: significantly increased risk of leukemia, brain and stomach cancers; (reduced risk of prostate cancer)
  - women with IDD: significantly increased risk of leukemia, corpus uteri and colorectal cancers (Sullivan et al., 2004)
Reproductive Cancers Among Women with IDD: Protective Factors

- Low estrogen levels in some women with ID reduce the risk of cervical cancer and some types of breast cancer (Valk, Schupf, & Patja, 2002)

- Some women with ID experience an earlier menopause, which decreases risk of breast cancer (Willis, Satgé & Sullivan, 2011)

- Risk of cervical cancer is reduced with the absence of sexual intercourse (Valk et al., 2002)
  - Sexual intercourse heightens risk for HPV

- Breast cancer is reduced for women with Down syndrome (Willis, Satgé & Sullivan, 2011)
Reproductive Cancers Among Women with IDD: Risk Factors

- Obesity (Willett, 2001)
- Nulliparity
- Increased risk of sexual assault (Parish et al., 2013)
- An estimated 68-83% of women with IDD sexually assaulted during lifetime, compared to 18% of nondisabled women (Tyiska, 1998; Tjaden & Thoennes, 2006)
Cervical & Breast Cancer Among Women with IDD: Risk Factors

- **MAJOR** risk factor is decreased rates of screening for both breast and cervical cancer among women with IDD.

- Pap test is the screening tool for cervical cancer.

- Women with IDD 72% less likely than women without disabilities to have received Pap tests.

- Mammogram is the screening tool for breast cancer.

- 45% less likely than women without disabilities to have received mammography (Parish & Saville, 2006).
Disparities in reproductive cancer experience for women with IDD

- Little is known about cancer hospitalization among women with IDD
- Most research focuses on screening, and some explores explaining a cancer diagnosis to someone with IDD
Disparities in reproductive cancer experience for women with IDD

- Women with IDD present with breast tumors at an earlier age, and of a higher cancer stage (Satgé et al., 2014)

- Why?
Our Study

- Exploratory study

- Aims:
  - Determine the relative prevalence of reproductive cancer hospitalization
  - Identify characteristics of women receiving this treatment
Our Study

- Data were drawn from the 2009 Healthcare Cost and Utilization Project (HCUP)
  - Nationally representative of hospital discharges (n=1,288 women with ID)
- IDD identified by ICD-9 diagnostic codes
- We compared hospitalizations for women with and without IDD controlling for:
  - Age, race, insurance payer, median household income for the patient’s zip code, type of cancer, length of stay, died in hospital, and total hospital charges
Limitations of HCUP

- Duplication: If a woman hospitalized twice in the same year, she is in the sample twice.
- Reliance on ICD-9 codes: likely there is under-ascertainment of women with IDD from the dataset.
## Description of the Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Women with IDD n = 1,288</th>
<th>Women without IDD N= 499,462</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>77%</td>
<td>76%</td>
</tr>
<tr>
<td>Black</td>
<td>11%</td>
<td>12%</td>
</tr>
<tr>
<td>Latina</td>
<td>7%</td>
<td>7%</td>
</tr>
<tr>
<td>Median Age***</td>
<td>55 yrs</td>
<td>66 yrs</td>
</tr>
<tr>
<td>Medicare***</td>
<td>68%</td>
<td>60%</td>
</tr>
<tr>
<td>Medicaid***</td>
<td>20%</td>
<td>10%</td>
</tr>
<tr>
<td>Live in a zip code with median income below $38,999**</td>
<td>32%</td>
<td>25%</td>
</tr>
<tr>
<td>Mean hospital stay length***</td>
<td>6.78 days</td>
<td>5.53 days</td>
</tr>
</tbody>
</table>

*p < .05.  **p < .01.  ***p < .001
Findings – Percent of Patients

Women with IDD vs Women without IDD

Breast: 30 vs 31
Ovary: 6 vs 5
Other female genital organs: 1 vs 1
Cervix: 2 vs 4
Uterus: 8 vs 6
Hospitalization with principal diagnosis of cancer: 5 vs 11

*p < .05. **p < .01. ***p < .001
Findings

- Women with IDD who were hospitalized for cancer treatment were significantly younger (mean=55 years) than women without IDD (mean = 66 years)

- Women with IDD were more likely than other women to have public (Medicaid or Medicare) insurance coverage

- Women with IDD had longer mean hospital stays (6.8 v. 5.5 days)
Findings

- Women with IDD also were much more likely to live in zip codes with low median income.

- Cancer of the uterus was more prevalent for women with ID than other women (8% vs. 6% of cancer hospitalizations).

- Cancer of the cervix was less prevalent for women with ID than other women (2% vs. 4% of cancer hospitalizations).
In conclusion, some questions...

- Why are women with IDD significantly younger when they are hospitalized for cancer treatment?
- Why are women with IDD significantly less likely to be hospitalized with a primary diagnosis of cancer?
- Why is the prevalence of uterine cancer higher for women with IDD?
- Why do women with IDD have longer cancer treatment hospital stays than women without IDD?

The need to understand cancer among people with IDD is urgent
References


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➢ www.lurie.brandeis.edu

Thank you!

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