

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

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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 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

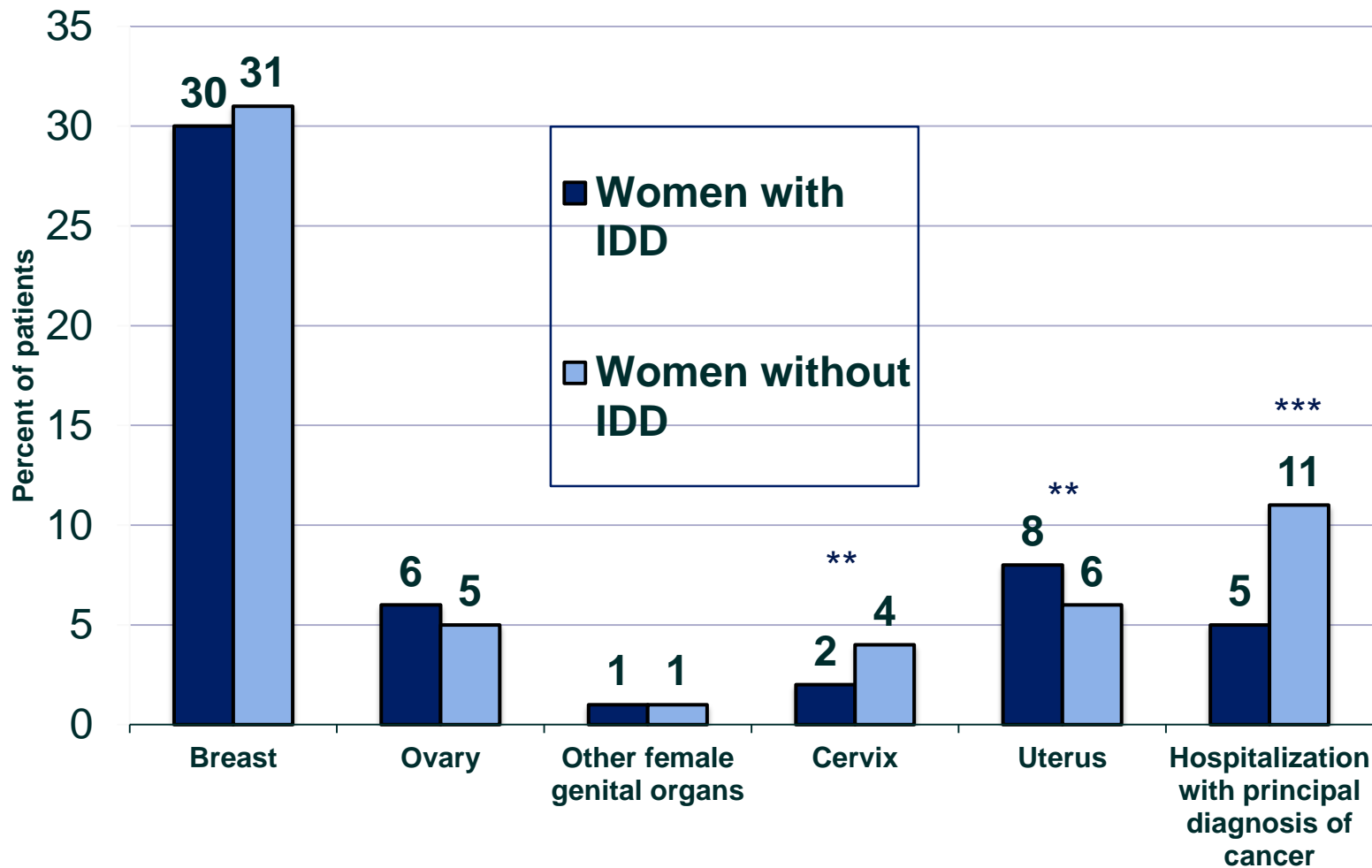
Description of the Sample

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

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



Findings – Percent of Patients



*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% v. 6% of cancer hospitalizations)
- Cancer of the cervix was less prevalent for women with ID than other women (2% v. 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

CDC. (2015). *Leading Causes of Death*.

Parish, S. L., & Saville, A. W. (2006). Women with cognitive limitations living in the community: Evidence of disability-based disparities in health care. *Mental Retardation*, 44, 249-259.

Satgé, D., Forbat, L., & Merrick, J. Cancer in people with intellectual disability. (2008). Are we ready? *Int J Disabil Hum Dev*, 7(4), 363-4.

Satgé D, Sasco AJ, Azema B, Culine S: Cancers in persons with intellectual deficiency: current data. In *Mental retardation research focus*. Edited by Charleton MV. New York: Nova Sciences Publisher; 2007:47–84.

Satgé, D., Sauleau, E. A., Jacot, W., Raffi, F., Azema, B., Bouyat, J. C., & El Hage Assaf, N. (2014). Age and stage at diagnosis: a hospital series of 11 women with intellectual disability and breast carcinoma. *BMC Cancer*, 14, 150. doi: 10.1186/1471-2407-14-150

Sullivan, S. G., Hussain, R., Threlfall, T., & Bittles, A. H. (2004). The incidence of cancer in people with intellectual disabilities. *Cancer Causes Control*, 15(10), 1021-1025.

Tjaden, P. G., & Thoennes, N. (2006). Extent, nature, and consequences of rape victimization: Findings from the National Violence against Women Survey (National Criminal Justice Publication No. 210346). Washington, DC: U.S. Department of Justice, Office of Justice Programs

Tyiska, C. G. (1998, September). Working with victims of crime with disabilities. Washington, DC: U.S. Department of Justice, Office of Justice Programs. Retrieved from <http://www.ojp.usdoj.gov/ovc/publications/factshts/disable.htm>

Valk, H., Schupf, N., & Patja, K. (2002). Reproductive and physical health. In P. Noonan-Walsh & T. Heller (Eds.), *Health of women with intellectual disabilities* (pp. 22–40). Oxford, England: Wiley-Blackwell.

Wacker, J., Macy, R., Barger, E., & Parish, S. (2009). Sexual assault prevention for women with intellectual disabilities. *Intellectual and Developmental Disabilities*, 47, 249–262.

Willett, W.C. (2001). Diet and breast cancer. *J Intern Med*, 249, 395–411.

Willis, D.S., Satgé, D., & Sullivan, S.G. (2011). Breast cancer surveillance. In D. Satgé & J. Merrick (Eds.), *Cancer in children and adults with intellectual disabilities: Current research aspects* (pp. 103-111). New York: Nova Science.

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Thank you!

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