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Female Sterilization and Cognitive Disability in the United States, 2011–2015

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Abstract

OBJECTIVE—To compare female sterilization among three mutually exclusive groups of women: 1) women without any self-reported disability; 2) women with non-cognitive disabilities (sensory or physical disabilities); and 3) women with cognitive disabilities.

METHODS—We conducted a secondary analysis of nationally-representative data from the National Survey of Family Growth 2011–15, which surveyed women aged 15–44 in the U.S. civilian population. Disability status (self-reported) was ascertained using a standard set of questions about hearing, vision, cognitive, ambulatory, self-care, and independent-living difficulties. Regression models were used to calculate odds of female sterilization, hysterectomies and age of sterilization, while accounting for sociodemographic differences.

RESULTS—Female sterilization rates were higher among women with cognitive (22.1%, n=272) and non-cognitive disabilities (24.7%, n=150) than among women without disabilities (14.8%, n=1,132). After adjusting for sociodemographic covariates, women with cognitive disabilities had significantly higher odds of female sterilization (aOR=1.54, 95% CI 1.19–1.98, p<.01), and hysterectomy (aOR=2.64, 95% CI 1.53–4.56, p<.001) than women without cognitive disabilities. Women with cognitive disabilities also underwent sterilization at significantly younger ages (27.3 years, 95% CI 27.0–27.6) than women with non-cognitive disabilities (28.3 years, 95% CI 27.9–28.8) and women without any disability (29.8 years, 95% CI 29.5–30.0).

CONCLUSION—United States women with cognitive disabilities were more likely to have undergone female sterilizations and hysterectomies and at younger ages than women with other disabilities or without disabilities. Drivers of these disability-related differences in female sterilization patterns must be explored.

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INTRODUCTION

Female sterilization is the most common method of contraception in the United States.¹ Rates of female sterilization procedures, which include surgical procedures (tubal ligation or hysterectomy) and nonsurgical procedures (tubal occlusion), vary by sociodemographic characteristics including age, race, ethnicity, income and insurance status.^{2–4} For instance, Native American and African American women were more likely to undergo surgical sterilization compared to non-Hispanic White women.⁴ Those with public or no insurance were more likely than those with private insurance to undergo tubal sterilization.² These reports show that reproduction and sterilization is shaped by socioeconomic status and race and ethnicity, possibly through medical bias and social pressure to limit fertility.⁴

Very few studies examined associations between disability, female sterilization and hysterectomy using nationally representative data.^{5, 6} Using data from the 2011–13 National Survey of Family Growth, Wu and her colleagues⁶ reported that among women ages 15 to 44 years, those with sensory or physical disabilities had higher odds (aOR 1.36, 95% CI 1.03–1.79) of sterilization than their nondisabled counterparts.⁶ However, women with cognitive disabilities were excluded and the study could not make robust comparisons between groups because of sample size limitations. To address this research gap and better understand the association between cognitive disability and female sterilization, the present study aims to compare overall female sterilization, hysterectomies and age of sterilization in three mutually exclusive groups: 1) women without any disabilities; 2) women with non-cognitive disabilities; and 3) women with cognitive disabilities, who may or may not have other co-occurring disabilities.

MATERIALS AND METHODS

This study was a secondary analysis of data from the National Survey of Family Growth (NSFG). The NSFG is sponsored by the Centers for Disease Control and Prevention, and is a national cross-sectional survey on family life, marriage, divorce, pregnancy, infertility, use of contraception, and men's and women's health. NSFG participants are women and men aged 15–44 years. The survey results are intended for use by the U.S. Department of Health and Human Services and various stakeholders to plan policy, health services and health education programs, and study families, fertility, and health.⁷

For the 2011–15 NSFG, interviews were conducted between September 2011 and September 2015, via computer-assisted personal interviews in respondents' homes. The overall weighted response rate in NSFG 2011–15 was 71%.⁷ Teenagers and Black and Latino individuals were purposefully oversampled. The research protocol was evaluated by our university's Institutional Review Board, who determined that this work does not meet the federal definitions of “research” and provided us written permission to go ahead.

We combined data from two cycles of the NSFG (2011–13 and 2013–15) to increase the sample and thus the power to detect statistically significant differences between disability groups. The NSFG employs a continuous data collection scheme with year-round interviews, making it appropriate to conceptualize the two combined cross-sections as one continuous

entity, which we refer to as the “2011–15 NSFG” in this paper. The 2011–15 NSFG sample included both women and men but we excluded men, yielding a sample of women (n=11,300) with and without disabilities.

To examine women for whom sterilization was a pertinent option, we excluded women who were pregnant (n=487), trying to become pregnant (n=484), or medically sterile (e.g. postmenopausal) or surgically sterile (n=327) for non-contraceptive reasons (e.g., hysterectomies for reported medical indications such as fibroids or uterine cancer), or had male partners who were medically or surgically sterile (n=29). Finally, women who did not respond to the disability questions were excluded (n=2). This procedure yielded a final analytic sample of 9,971 women aged 15–44 years.

The primary independent measure was self-reported disability, which was ascertained in the NSFG through a series of six questions, developed by the U.S. Census Bureau for the American Community Survey (ACS).⁸ These six ACS questions seek to identify respondents who had: (1) serious difficulty hearing, (2) serious difficulty seeing even when wearing glasses, (3) difficulty processing information or making decisions, (4) difficulty walking or using stairs, (5) difficulty dressing or bathing, and (6) difficulty doing errands alone. Though not perfect, this set of questions went through rigorous testing and were shown to generate reliable prevalence estimates of people with different disabilities.⁸ From these six non-mutually-exclusive indicators, we created three mutually-exclusive groups: (1) no disability, which included women who did not report difficulty with any of the six indicators; (2) cognitive disabilities, which included women who reported difficulty processing information or making decisions, with and without other reported difficulties; and (3) non-cognitive disabilities, which included women who reported positively to at least one of the other disability questions. Figure 1 describes the cohort selection process. Informed by previous studies,^{6, 9, 10} our statistical models controlled for the following covariates: age (years), race and ethnicity (Non-Latino White, Non-Latino Black, Latino, Other), health insurance status, household income, education, parity, marital status, and self-reported general health status.

There were three outcomes of interest: (1) sterilization status, (2) age at sterilization, and (3) whether the woman had a hysterectomy. Female sterilization status was determined from the NSFG variable “current contraceptive status”. Age of sterilization was calculated by subtracting date of birth from date of sterilization, and dividing by 12 months. Hysterectomy status was identified from the survey question “Have you ever had a hysterectomy, that is, surgery to remove your uterus?” The question was applicable to all women respondents if they were not pregnant at the time of the survey.

We accounted for the multi-stage, probability-based complex sampling design, including oversampling of subpopulations and nonresponse in all analyses by using the following variables provided by the NSFG: the stratum variable SEST, the cluster variable SECU and the final weight variable WGT2011_2015. The Stata “svy” commands were used. Taylor-series estimated weighted percentages and logistic regression estimated odds ratios (OR) with 95% confidence intervals were reported. All analyses were conducted with Stata MP 15.1.¹¹

RESULTS

We present descriptive statistics and bivariate comparisons in Table 1. The three groups of women (with no disabilities, non-cognitive disabilities, or cognitive disabilities) varied significantly on several characteristics. Age distribution differed greatly. Women with non-cognitive disabilities were the oldest group, and women with cognitive disabilities were the youngest. Race and ethnicity was similar overall, with the exception that women with non-cognitive disabilities were more likely to be Black in contrast to women with no disabilities and cognitive disabilities. Women with cognitive disabilities had less education, were more likely to have Medicaid or be uninsured, and were most likely to have income below the Federal Poverty Level. Women with cognitive disabilities were also less likely to be married at the time of survey. Women with non-cognitive disabilities were most likely to report being in fair or poor health and they had the highest levels of parity. Overall, the two groups of women with disabilities had similar socioeconomic and health status.

Both groups of women with disabilities had higher sterilization rates than women without any disabilities (24.7% among those with non-cognitive disabilities, 22.1% cognitive disabilities vs. 14.8% no disabilities, $p<.05$). Table 2 showed that both groups of women with disabilities were significantly younger when they were sterilized (mean ages 28.3 and 28.5 vs. 30.1 years, $p=.0501$ and $p<.05$, respectively), and had higher rates of hysterectomy than women without any disabilities (6.2% and 6.0% vs. 2.2%, $p<.05$). Women with either cognitive or non-cognitive disabilities also had higher rates of receiving any type of sterilization (tubal ligation, hysterectomy, both, or other).

Table 3 presents the multivariate regression results. After adjusting for all model covariates, the odds of sterilization were about 1.5 times higher among women with cognitive disabilities compared to women without disabilities (aOR=1.54, 95% CI 1.19–1.98, $p<.01$). The odds of receiving a hysterectomy were 2.6 times greater among women with cognitive disabilities compared to women without disabilities (aOR=2.64, 95% CI 1.53–4.56, $p<.001$). Women with cognitive disabilities underwent sterilization at significantly younger ages (regression-adjusted age = 27.3 years, 95% CI 27.0–27.6; Figure 2) than women with non-cognitive disabilities (28.3 years, 95% CI 27.9–28.8) and women without any disability (29.8 years, 95% CI 29.5–30.0). We found no significant differences in the odds of sterilization, hysterectomy, or age of sterilization between women with non-cognitive disabilities and women without disabilities.

DISCUSSION

The comparisons of overall female sterilization, hysterectomies and age of sterilization in the three groups revealed clear differences between U.S. women with and without cognitive disabilities aged 15–44 years. The results of the regression analysis suggested that there may exist non-medical, non-sociodemographic links between sterilization and cognitive disability. Once such link may be the historic remnant of systematic oppression. Historically, forced sterilization was used as a coercive tool to control the bodies and limit the reproductive autonomy of marginalized people in the United States, including minorities, poor people, immigrants, prisoners and people with disabilities.¹² At the height of the U.S.

eugenics movement in the early twentieth century, the majority of involuntary sterilizations were performed on institutionalized women with cognitive or multiple disabilities.^{13, 14} While we cannot assume every single case of sterilization is involuntary or oppressive, this increased rate of sterilization among community-living women with cognitive disabilities is still potentially alarming, considering the many different kinds of effective alternatives that are available today.

The comparisons also support existing research on hysterectomy and disability. Earlier studies have shown that women with any type of disability experience an increased risk of hysterectomy,⁵ and young women with cognitive disabilities are at greatest risk.^{5, 13, 15} A recent study of 42,842 women from the National Health Interview Survey found that young women with multiple disabilities, especially women ages 21 to 25 years of age, experience the greatest risk of hysterectomy compared to their counterparts with a single disability or no disabilities. This raises questions about whether hysterectomies are conducted out of medical necessity, or for reasons such as menstrual management, preventing pregnancy or childbearing.⁵

Our analysis also found that women with cognitive disabilities were more likely to be sterilized at an earlier age than women with no disabilities and women with different types of disabilities. It is striking that this finding is not explained by socioeconomic disadvantages or poorer health status, as women with non-cognitive disabilities face similar disadvantages, but did not show similar sterilization outcomes.

Overall, these findings support existing literature on the disparities faced by women with cognitive disabilities.^{5, 13} Additionally, the present study complements Drew⁵ in demonstrating that women with cognitive disabilities are more likely to receive hysterectomy instead of tubal ligation or salpingectomy. Finally, the present study fills an important gap in the literature by examining the age of sterilization among women with and without cognitive disabilities.

Limitations

The findings of this study should be evaluated within the context of the study limitations. The NSFG excludes the institutionalized populations, who may have more severe disabilities and experience different rates of sterilization. The data in the NSFG rely on self-report and are not validated by objective clinical sources. While prior research has found that women with intellectual and developmental disabilities are accurate reporters of reproductive health procedures,¹⁶ future research could fruitfully examine sterilization with non-subjective, clinical data.

Publicly available NSFG data do not include the reasons why women had sterilization or hysterectomy. The eugenic enthusiasm for sterilizing women with mental disabilities in the United States suggests that medical reasons do not necessarily drive sterilization for these women, but this speculation should be further explored with data that are more detailed.

Finally, even though we combined two NSFG cross-sections to form a larger dataset, there were still small cell sizes (i.e. hysterectomies among women with non-cognitive disabilities),

which, considering the number of adjustors, were not ideal for regression analysis as the model may have been over fitted for this subset. The other analyses had sufficient numbers and did not have similar issues.

Implications

Having access to the most appropriate sterilization method is an important aspect of comprehensive reproductive healthcare for women with and without disabilities. For some women with disabilities, sterilization is their preferred and best contraceptive method. However, prejudice and discrimination against women with cognitive disabilities is longstanding and, if unchecked, could result in unequal treatment or biased decisions in the form of involuntary sterilization, unnecessary hysterectomies and early sterilization.

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Figure 1.
Disability groups determination process.

Figure 2.

Adjusted age of female sterilization by disability status (years). Adjusted age calculated using logistic regressions, which control for age, race and ethnicity, education, health insurance status, poverty status, marital status, parity, and self-rated health status. Error bars indicate the 95% CIs.

Table 1Selected characteristics of U.S. females aged 15–44 by presence and type of disabilities ^{*}

Selected Characteristics (Total N=9,971)	No disabilities n=8,021 (80.4%)	Non-Cognitive Disabilities [†] n=642 (6.4%)	Cognitive disabilities [‡] n=1,308 (13.1%)	Significant Pairwise Differences [§] (p<.05)
Age^{//}				
15–24	33.8	26.4	42.6	<i>a,b,c</i>
25–34	33.7	30.8	29.3	<i>c</i>
35–44	32.5	42.7	28.1	<i>a,b</i>
Race and ethnicity				
Non-Hispanic White	56.6	51.1	52.5	-
Non-Hispanic Black	13.2	21.9	12.6	<i>a,b</i>
Hispanic	19.8	18.4	23.0	-
Other	10.4	8.6	11.9	-
Education				
Bachelor's degree or higher	30.3	17.0	8.3	<i>a,b,c</i>
Some college, no Bachelor's degree	30.7	30.6	24.9	<i>c</i>
High School Diploma or GED	21.7	32.7	34.1	<i>a,c</i>
Some High School	17.3	19.7	32.7	<i>b,c</i>
Current Medical Insurance				
Private	63.4	44.7	38.7	<i>a,c</i>
Medicaid, CHIP, state-sponsored health plan	15.4	27.1	31.8	<i>a,c</i>
Medicare	3.9	7.9	5.9	<i>a,c</i>
Underinsured or uninsured	17.2	20.3	23.6	<i>c</i>
Income				
>200% FPL	54.0	38.7	32.1	<i>a,c</i>
100–199% FPL	20.7	23.8	21.0	-
<100% FPL	25.3	37.5	46.9	<i>a,b,c</i>
Marital Status				
Single	48.9	49.7	63.8	<i>b,c</i>
Living with male partner, unmarried	13.6	14.7	13.9	-
Married	37.5	35.5	22.2	<i>b,c</i>
Parity				
Parous	54.0	68.0	51.6	<i>a,b</i>
Self-reported general health^{//} N=9,945				
Fair or Poor	4.8	21.5	17.1	<i>a,c</i>

Notes:

^{*} Data are from National Survey of Family Growth (NSFG) 2011–15.[†]“Non-Cognitive Disabilities” refer to serious difficulties in hearing, seeing, walking or climbing stairs, dressing or bathing, or doing errands alone.[‡]“Cognitive disabilities” refer to “serious difficulty concentrating, remembering or making decisions”.[§]In the pairwise comparisons, the contrasts between the groups of women that were statistically significant (p<.05) are denoted as follows:

a= women with no disabilities vs. women with non-cognitive disabilities,

b= women with non-cognitive disabilities vs. women with cognitive disabilities,

c= women with no disabilities vs. women with cognitive disabilities.

// Weighted percentages are reported. GED=general education degree, CHIP=Child Health Insurance Program. “Underinsured” refers to coverage “only by a single-service plan” or “only by the Indian Health Service”. “FPL” refers to Federal Poverty Level, a household-based income threshold issued annually by the U.S. Department of Health and Human Services.

// Because of data reported as missing or inapplicable, self-reported general health ended up with a slightly smaller sample size, which is noted.

Table 2

Unadjusted percent of U.S. women aged 15–44 sterilized, stratified by disability status and type

Sterilization Characteristics (Total N=9,971)	No Disabilities	Non-Cognitive Disabilities	Cognitive Disabilities	Significant Pairwise Differences* (p<.05)
	n=8,021 (80.4%)	n=642 (6.4%)	n=1,308 (13.1%)	
Ever sterilized	14.8	24.7	22.1	<i>a,c</i>
Age when sterilized (Mean years)	30.1	28.3	28.5	<i>a[†], c</i>
Sterilization method				
Tubal	13.7	23.7	20.3	<i>a,c</i>
Hysterectomy	2.2	6.2	6.0	<i>a,c</i>
Both	1.4	5.3	4.5	<i>a,c</i>
Other	0.3	0.2	0.7	-

Notes:

*
In the pairwise comparisons,

a= no disabilities vs. non-cognitive disabilities, p<.05

a[†]= no disabilities vs. non-cognitive disabilities, p=.0501

b= non-cognitive disabilities vs. cognitive disabilities, p<.05

c= no disabilities vs. cognitive disabilities, p<.05

Table 3

Adjusted Odds Ratios and 95% Confidence Intervals (CI) of Women's Sterilization

	aOR [*]	aOR CI
Any Female Sterilization		
Non-cognitive disabilities	1.04	(0.70–1.57)
Cognitive disabilities	1.54 [†]	(1.19–1.98)
Hysterectomy		
Non-cognitive disabilities	1.65	(0.96–2.84)
Cognitive disabilities	2.64 [‡]	(1.53–4.56)

^{*}“aOR” stands for (regression) adjusted odds ratio(s). Women without disabilities were the reference group. Regression models control for age, race and ethnicity, education, health insurance status, poverty status, marital status, parity, and self-rated health status.

[†]p<.01

[‡]p<.001