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Conditions Causing Disability and Current Pregnancy Among U.S. Women with Chronic Physical Disabilities

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Abstract

Background—Growing numbers of reproductive-age U.S. women with chronic physical disabilities (CPD) are becoming pregnant. Little is known about the health conditions causing their CPD.

Objectives—To identify health conditions causing CPD among reproductive-age women and specifically among currently pregnant women.

Research Design—Cross-sectional, nationally-representative National Health Interview Survey data from 2006–2011.

Subjects—6,043 civilian, noninstitutionalized women ages 18–49 with CPD

Measures—NHIS asks about various movement difficulties and their underlying causes and about current pregnancy. We used responses from 8 movement difficulty and other questions to identify women with mobility difficulties caused by chronic physical health conditions.

Results—Among women with CPD, 2.0% report current pregnancy, with pregnancy rates falling monotonically as CPD severity rises. Regardless of pregnancy, 20.8% report 2 causes for their CPD, and 12.7% report 3+ causes; the most common causes are arthritis, back or neck problems, and other musculoskeletal conditions. Compared with nonpregnant women, currently pregnant women report fewer causal conditions: 15.8% report 2 causes and 8.0% 3+ causes; back or neck problems are reported most frequently, followed by musculoskeletal problems and arthritis. Multivariable logistic regression analyses predicting current pregnancy controlling for age category and individual common causes of CPD found that no cause was significantly associated with higher or lower adjusted odds of pregnancy.

Conclusions—Almost one-quarter of currently pregnant women with CPD report more than one cause for their disability. Further research will need to examine how obstetrical needs vary for depending on the cause of a pregnant woman's disability.

Keywords

disability; pregnancy; mobility; comorbidities; National Health Interview Survey

Anecdotal evidence suggests that growing numbers of American women with chronic physical disabilities (CPD) are becoming pregnant.¹ Recent analyses of national survey data found that approximately 163,700 U.S. women with CPD are pregnant at some point each year, including nearly 44,200 women reporting severe physical disabilities.² In coming decades, the population of reproductive-age women with CPD will increase,^{3–6} likely resulting in rising numbers of pregnancies. Therefore, learning more about the obstetrical needs of women with CPD is critical.

Here we define CPD as chronic functional impairments of upper or lower extremities that limit mobility. These functional impairments may themselves affect pregnancy outcomes. In addition, the health conditions causing the impairments might contribute to obstetrical risks. For example, during pregnancy, healthy women with spinal cord injury might need specific services (e.g., intensive monitoring of skin integrity in ischial areas), which differ from those of ambulatory pregnant women with multiple sclerosis initially taking powerful disease-modifying drugs. In anticipating their specific clinical needs, understanding the nature of disabling health problems among pregnant women with CPD is essential.

Few data sets contain information on current pregnancy and women's disabling health conditions. The federal, cross-sectional National Health Interview Survey (NHIS) includes self-reported "current" pregnancy, mobility-related functional limitations, and self-reported causes of these functional limitations. Using NHIS data, we address two primary research questions: (1) What are the self-reported causes of their functional impairments for reproductive-age U.S. women with CPD? (2) and What are the associations between these underlying causes and current pregnancy among women with CPD? Although these data are only descriptive, they offer an important starting point for understanding potential clinical needs of pregnant women with CPD.

Methods

Data

Another publication describes our data and CPD measure in detail.² Briefly, we used 2006–2011 NHIS Public Release data from the National Center for Health Statistics (NCHS). NHIS surveys U.S. civilian, noninstitutionalized, community residents, oversampling black, Hispanic, and Asian populations. Applying NHIS sampling weights produces nationally representative figures. The NHIS Basic Module contains 3 components: Family Core, Sample Adult Core, and Sample Child Core. The Family Core collects information on all family members. Within each family, one randomly selected adult (age ≥ 18) receives the Sample Adult Core survey, which asks detailed health and functional status questions. A knowledgeable adult family member provides proxy responses for sampled adults who are physically or mentally unable to respond. The 2011 NHIS Sample Adult Core, for example, included 33,014 individuals; 465 had proxy responses.⁷ The conditional response rate for the Sample Adult Core was 81.6%.⁷ We drew our study population from the 157,351 total participants in the 2006–2011 Sample Adult Core surveys, which all had similar numbers of participants and response rates.

The Sample Adult Core asks women ages 18–49 whether they are "currently pregnant." As detailed elsewhere,² we first selected the 47,886 women ages 18–49 and then eliminated women with: missing responses to the pregnancy question (0.2%); no responses to the 8 functional status questions for determining CPD (0.3%); and reported Alzheimer's disease (7 women). Our final sample of 47,629 women had 263 (0.6%) proxy respondents.

Chronic Physical Disability Indicator

To determine CPD,² we began with NCHS's "movement difficulty severity" algorithm.⁸ It uses responses to questions about difficulties caused by health problems with: walking a quarter mile; walking up 10 steps without resting; standing for about 2 hours; sitting for about 2 hours; stooping, bending, or kneeling; reaching up overhead; using fingers to grasp or handle small objects; and lifting or carrying something as heavy as 10 pounds. The question stem asks respondents not to report difficulties caused by pregnancy. The NCHS algorithm considers only responses indicating "somewhat difficult" or worse difficulties. Each activity is weighted based on its presumed importance for maintaining independent lifestyles. The movement difficulty algorithm has 5 severity levels (1 to 5, from least to most severe).

We refined our CPD indicator as follows:² First, despite requests that women not report pregnancy-related difficulties, 138 (2.0%) indicated in later questions that pregnancy had caused their impairments; we eliminated these cases from our CPD group. Second, we eliminated women (4.1%) who reported that conditions other than physical health problems (e.g., intellectual disabilities, psychiatric or mental health problems, substance abuse) caused their movement difficulties. Finally, we removed women (4.8%) who reported their underlying health problem was not "chronic." After these refinements, our final sample included 6,043 women (12.7%) with CPD. Because of small numbers with the highest severity level impairments,² we combined cases across levels 3–5.

Causes of Disability

After asking about functional difficulties, the Sample Adult Core queries respondents about the condition(s) that caused their difficulties; respondents can report more than one condition. The survey lists 35 possible health causes, along with an open-ended option (coded for Public Release files). As noted above, we excluded from our CPD group women who listed causes that are not physical health problems.² Because of small sample sizes, we grouped together some causes for analysis.

Other Variable Definitions

To describe the study population, we report key sociodemographic characteristics (Table 1). All variables come from the Sample Adult Core except for family poverty, which is from the Family Core.

Analysis

All analyses used SAS Version 9.2 (Cary, NC) and employed NHIS sampling weights to produce nationally-representative figures, including percentages. Because of strong relationships between age and disability level and between age and pregnancy,² we used direct standardization to adjust certain demographic characteristics by age category (Table 1). We used χ^2 tests to assess bivariable associations. For each underlying cause with 15 respondents reporting current pregnancy, we conducted two multivariable logistic regressions with current pregnancy as the dependent variable and the following predictor dummy variables: (1) age category + specific cause; and (2) age category + specific cause + indicator of 2 or more causes. We report adjusted odd ratios (AORs) and 95% confidence intervals from these analyses. Small numbers of pregnancies precluded more complex multivariable analyses.

Results

Demographic Characteristics and Current Pregnancy

Table 1 shows basic demographic characteristics of U.S. women ages 18–49 with CPD. As CPD severity increases, women are significantly more likely to be: older; black; divorced or separated; less educated; and living below the federal poverty level. Among all women with CPD, 2.0% report current pregnancy, with pregnancy rates falling significantly and monotonically as CPD severity rises.

Health Conditions Causing CPD

Table 2 shows the number (percent) of women by CPD severity level and by current pregnancy who attribute their CPD to each of 11 causes (we grouped relatively rare causes into “miscellaneous” and “other” categories). The most common causes are arthritis, back or neck problems, and other musculoskeletal conditions. Respondents could list more than one health cause for their self-reported functional impairments. Among all women, 20.8% report 2 causes, and 12.7% report 3 or more (largest number = 14 causes). Compared with others, women with the most severe CPD report much higher rates of arthritis, nervous system or other sensory organ conditions, and cardiovascular conditions. While only 3.3% of women with the least severe CPD report 3 or more causes, 24.7% of the most severely disabled women report multiple causes.

Currently pregnant women with CPD report back and neck problems most frequently, followed by musculoskeletal problems and arthritis (Table 2). However compared with disabled women overall, currently pregnant women with CPD report fewer causal conditions. Table 3 presents findings from multivariable logistic regression models predicting current pregnancy based on age category and reported cause(s) of CPD. None of the AORs are statistically significant. These findings suggest that no causal condition – nor the presence of 2 or more causes – is associated with either higher or lower likelihoods of current pregnancy among women with CPD.

Discussion

Women with chronic physical disabilities report various health conditions as underlying their functional impairments, with one-third reporting 2 or more causes. Women with CPD who are currently pregnant report a similar range of underlying health conditions, although slightly less than one-quarter report 2 or more causes. Among the most common causes, none appears to be significantly associated with higher or lower likelihood of current pregnancy. Reporting 2 or more causal conditions is also not significantly associated with the adjusted odds of being currently pregnant.

Obstetrical needs are likely closely tied to the health condition(s) causing the woman’s CPD. Our findings suggest that large subsets of currently pregnant women with CPD are disabled by musculoskeletal problems or arthritis, not surprising given the widespread prevalence of these conditions. Smaller subgroups among pregnant women have neurological, pulmonary, weight problems, or other health conditions.

A small body of literature discusses clinical considerations for pregnancy among women with specific physical disabilities. These publications suggest that different disabling conditions raise differing obstetrical concerns. Many articles start with disclaimers about how little is known about pregnancy among women with CPD, such as spina bifida^{9, 10} and cerebral palsy.^{11, 12} One study found that women with rheumatoid arthritis or systemic lupus erythematosus have higher rates of hypertensive disorders during pregnancy.¹³ Women with juvenile idiopathic arthritis have high incidence of pre-eclampsia, post-partum hemorrhage,

and other obstetrical complications.¹⁴ Spinal cord injury predisposes pregnant women to particular complications, including: pyelonephritis and urosepsis; decubitus ulcers; autonomic hyperreflexia; deep venous thrombosis and pulmonary embolism; and diminished pulmonary function.^{15–26} In multiple sclerosis, some studies suggest fewer flares early in pregnancy followed by higher post-partum relapses and no change in long-term disability,^{27–33} but substantial evidence gaps remain.^{34–36} Maternal obesity can cause obstetrical complications for mothers^{37–39} and worse outcomes for neonates.^{40,41}

Our findings provide the first insight of which we are aware about the nature of underlying conditions among women with CPD generally and specifically among currently pregnant women with CPD. However, our data source, NHIS, has important limitations. NHIS does not contain information about pregnancy outcomes; the accuracy of the pregnancy indicator and self-reported underlying causes is unknown. In particular, although respondents are asked not to report functional limitations related to pregnancy, some reported causes – such as back or musculoskeletal problems or excess weight – could relate directly to pregnancy. Failure to find statistical associations between back and musculoskeletal problems may, however, make this concern less likely. NHIS relies entirely on self reports of functional difficulties and health conditions. Respondents may either over- or underreport their functional difficulties and health problems for a variety of reasons, including cultural factors and gender role expectations.

Although we used multiple years of data, the numbers of women with CPD are relatively small, and that subset who report current pregnancy is very small. The numbers of cases with specific health conditions were too small to conduct more complex analyses. Therefore, much more research is required to understand fully the disabling health conditions of pregnant women with CPD.

Despite these limitations, these data offer new evidence about the health conditions causing disability of U.S. women with CPD who are currently pregnant. Most striking are the multiple health problems potentially causing women's functional impairments. Our results suggest that women with CPD who become pregnant have diverse clinical needs necessitating highly individualized clinical responses. It is therefore imperative to understand better the role of various clinical disciplines in advising women with CPD about what to expect during pregnancy relating to their underlying health conditions. In addition, intensive preconception planning should aim to maximize women's overall health before they become pregnant. Multiple clinicians from different disciplines (e.g., obstetrics, other medical specialties, nursing, midwifery) may need to collaborate to provide integrated care responsive to pregnant women's preferences and diverse health conditions throughout their pregnancies and childbirths.

Considerable work remains to be done to understand pregnancy experiences and clinical needs of women with CPD. However, the small number of cases – even in the large NHIS – and the diversity of conditions causing CPD underscore how challenging research about clinical care for these women will be. Conducting rigorous investigations will likely require multi-center collaborations across obstetrical providers. Nonetheless, given that the number of U.S. women of reproductive age with CPD will likely grow in coming years, learning more about their obstetrical needs should be a priority to maximize their likelihood of having safe pregnancies and healthy children.

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Table 1

Demographic Characteristics and Pregnancy Rate by Chronic Physical Disability Severity

N = 6,043				
Characteristics	All	CPD severity		
		Low	Medium	High
Sample size: number of respondents	6,043	2,084	1,711	2,248
% of total sample in column	100.0%	34.5%	28.3%	37.2%
Age in years: mean (SD)	38.1 (0.2)	36.2 (0.3)	38.1 (0.3) *	39.9 (0.2) *
Age category: %				
18–24	10.9%	16.0%	11.1% *	5.7% *
25–29	9.2	12.6	8.8	6.1
30–34	11.4	11.7	11.4	11.1
35–39	15.7	15.3	14.4	17.2
40–44	21.9	18.9	24.3	23.0
45–49	30.9	25.7	30.0	36.9
Race: adjusted % ^a				
White only	77.5%	81.3%	76.7% [§]	74.2% *
Black only	16.6	13.0	16.6	20.4
Asian only	2.1	2.2	2.6	1.5
Other race including multiple	3.8	3.5	4.1	3.9
Ethnicity: adjusted % ^a				
Hispanic	13.0%	14.0%	12.6%	12.4% [#]
Not Hispanic	87.0	86.0	87.4	87.6
Marital status: ^b adjusted % ^a				
Single, never married	22.7%	24.2%	23.1% ⁺	20.9% *
Married/living with partner	58.8	62.0	58.8	55.8
Divorced/separated	17.0	13.1	16.9	20.8
Education: ^b adjusted % ^a				
Less than high school	18.5%	13.2%	18.6% *	23.7% *
High school	30.0	26.9	30.0	33.0
Some college, associate degree	36.0	37.2	37.0	34.1
College, more than college degree	14.8	22.4	14.0	7.9
Family income less than the poverty threshold: adjusted % ^a	23.8%	15.2%	23.1% *	33.1% *
Currently pregnant: adjusted % ^a	2.0%	2.6%	1.8% [#]	1.5% ⁺

p values for comparisons of women with low CPD severity versus medium or high severity

* p 0.0001

⁺ p 0.001

$\$$ _p 0.01

$\#$ _p 0.05

^a Percents adjusted by age category

^b Other and missing responses not shown

Table 2

Health Conditions Causing CPD by Current Pregnancy and CPD Severity

Chronic health conditions reported as cause of functional limitations ^a	All women				Currently pregnant women			
	All	CPD severity			All	CPD severity		
		Low	Medium	High		Low	Medium	High
	number (percent) ^b with condition							
Arthritis or rheumatism	1,689 (28.0)	388 (18.5)	447 (27.2)	854 (38.2)	21 (17.2)	7 (10.1)	4 (17.3)	10 (29.7)
Back or neck problems	2,209 (35.6)	703 (33.1)	576 (33.0)	930 (40.3)	47 (32.1)	22 (30.5)	13 (38.4)	12 (29.3)
Musculoskeletal and connective tissue problems	1,300 (22.1)	475 (23.9)	323 (19.5)	502 (22.3)	22 (17.8)	16 (25.8)	3 (13.4)	3 (7.5)
Fractures, bone or joint injuries, other injuries, or missing or amputated limb/finger/digit	1,019 (17.1)	332 (17.0)	286 (16.6)	401 (17.6)	13 (11.0)	6 (13.1)	6 (16.3)	1 (2.5)
Nervous system or sensory organ condition	666 (10.7)	89 (4.2)	188 (10.4)	389 (17.5)	15 (13.7)	4 (6.0)	7 (15.4)	4 (25.7)
Cardiovascular conditions (heart problems, hypertension, stroke, circulation problems)	644 (9.9)	84 (3.3)	165 (8.9)	395 (17.2)	12 (7.2)	3 (3.2)	4 (9.8)	5 (12.2)
Weight problems	622 (10.4)	175 (8.6)	223 (12.9)	224 (10.2)	19 (15.7)	8 (15.6)	8 (23.5)	3 (8.6)
Lung or breathing problems	475 (7.7)	75 (3.7)	150 (8.4)	250 (11.1)	13 (10.5)	4 (5.5)	3 (13.4)	6 (16.6)
Diabetes	229 (3.4)	20 (0.9)	42 (2.2)	167 (6.8)	2 (1.7)	0 (0)	1 (1.8)	1 (4.5)
Miscellaneous health conditions ^c	393 (6.2)	67 (2.8)	95 (5.4)	231 (10.1)	4 (1.9)	2 (1.7)	0 (0)	2 (4.0)
Other problems ^d	342 (6.1)	117 (6.2)	80 (4.5)	145 (7.2)	4 (6.7)	0 (0)	2 (4.7)	2 (20.5)
Two conditions	1228 (20.8)	283 (14.1)	403 (24.5)	542 (24.7)	19 (15.8)	4 (4.2)	7 (24.8)	8 (28.3)
Three or more conditions	821 (12.7)	66 (3.3)	182 (9.5)	573 (24.7)	11 (8.0)	3 (3.6)	5 (14.6)	3 (9.7)

^a After questions about functional limitations, NHIS asks, "what condition or health problem causes you to have difficulty?" Respondents can report more than one condition. Respondents are then asked how long the condition has lasted. Numbers here show only conditions reported as "chronic."

^b Percent of the 6,043 women with CPD who report specific causes for their functional impairments. Respondents can report more than one cause; therefore, percentages (which are all adjusted by NHIS sampling weights) across conditions add to > 100

^c Cancer, benign tumor/cyst, endocrine/nutritional/metabolic problems, digestive system problem, genitourinary system problems, skin/subcutaneous system problem, blood or blood-forming organ problems

^d Birth defect, other developmental problem, surgical after effects/medical treatment, "old age"/elderly/aging-related problem, fatigue/tiredness/weakness, other

Table 3

Adjusted Odds Ratios of Current Pregnancy by Health Condition Causing Chronic Physical Disability

Total n = 6, 043			
Chronic health conditions causing functional limitations ^a	Model 1 ^a	Model 2 ^b	
		Specific cause AOR	2+ causes AOR
	Adjusted odds ratio (95% confidence interval)		
Arthritis or rheumatism	0.93 (0.5, 1.7)	1.00 (0.6, 1.8)	0.78 (0.5, 1.3)
Back or neck problems	0.89 (0.6, 1.4)	0.93 (0.6, 1.5)	0.79 (0.5, 1.3)
Musculoskeletal and connective tissue problems	0.77 (0.4, 1.4)	0.80 (0.4, 1.5)	0.80 (0.5, 1.4)
Nervous system or sensory organ condition	1.38 (0.7, 2.7)	1.58 (0.8, 3.1)	0.70 (0.4, 1.2)
Weight problems	1.53 (0.8, 2.8)	1.67 (0.9, 3.2)	0.72 (0.4, 1.2)
Two or more causal conditions	0.78 (0.5, 1.3)	---	---

^a Model 1: predictor variables are age categories and specific cause (yes/no). The final Model 1 enters 2+ causal conditions as a dummy variable.

^b Model 2: predictor variables are age categories, specific cause (yes/no), and 2+ causal conditions (yes/no). The right-most of the two Model 2 columns shows the AOR (95% CI) for the 2+ causal condition variable for each of the five condition-specific analyses.