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ORIGINAL ARTICLE

Current pregnancy among women with spinal cord injury: findings from the US national spinal cord injury database

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Study design: Cross-sectional study
Objectives: To examine the prevalence of pregnancy and associations with sociodemographic and clinical factors among women with spinal cord injury (SCI)
Setting: US National Spinal Cord Injury Database, an SCI registry that interviews participants 1, 5 and then every 5 years post injury. Data include SCI clinical details, functional impairments, participation measures, depressive symptoms and life satisfaction. Women aged 18–49 are asked about hospitalizations in the last year relating to pregnancy or its complications. Data represent 1907 women, who completed 3054 interviews.
Methods: We used generalized estimating equations to examine bivariable associations between pregnancy and clinical and psychosocial variables and to perform multivariable regressions predicting pregnancy.
Results: Across all women, 2.0% reported pregnancy during the prior 12 months. This annual prevalence differed significantly by the years elapsed since injury; the highest rate occurred 15 years post injury (3.7%). Bivariable analyses found that younger age at injury was significantly associated with current pregnancy ($P<0.0001$). Compared with nonpregnant women, those reporting current pregancy were significantly more likely to be married or partnered, have sport-related SCI, have higher motor scores and have more positive psychosocial status scores. Multivariable analyses found significant associations between current pregnancy and age, marital status, motor score and mobility and occupation scale scores.
Conclusion: Current pregnancy rates among reproductive-aged women with SCI are similar to rates of other US women with chronic mobility impairments. More information is needed about pregnancy experiences and outcomes to inform both women with SCI seeking childbearing and clinicians providing their care.
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INTRODUCTION

Significant improvements in health outcomes for individuals with spinal cord injury (SCI) over the last half century—and growing recognition that persons after SCI can live full, complex and rich lives—have made becoming pregnant an increasingly accepted and successful option for women with SCI.[1,2] SCI does not typically affect the ability of women to conceive. Furthermore, women with new SCI are generally young, early in their reproductive years. Nonetheless, other concerns may pose barriers to conception and childbirth, including both physical and psychosocial factors. Although studies have examined pregnancy and birth outcomes among women with SCI,[2–5]most involve small samples and retrospective data collection, which often does not capture critical clinical characteristics.[6]Thus, even basic information about pregnancy rates among women with SCI is unknown.

This research used the National Spinal Cord Injury Database (NSCID), funded by the National Institute of Disability Rehabilitation and Research, to study pregnancy among 1907 women with SCI treated at centers throughout the US. We examine pregnancy prevalence and associations with sociodemographic and clinical factors available in the NSCID. These data represent ~13% of individuals with new SCIs annually in the US.[7]

MATERIALS AND METHODS

Data source and study participants

NSCID is described in detail elsewhere.[7,8] Briefly, since its inception in 1973, NSCID has received information from 28 federally funded Spinal Cord Injury Model System centers, including patients' demographics, injury and medical characteristics and physical functioning during the initial hospitalization, rehabilitation and post-injury years 1, 5 and every 5 years thereafter. Each follow-up also gathers data on psychosocial well being and assistive technology. To qualify for NSCID and follow-up, individuals must have had a traumatic SCI, received acute care and inpatient rehabilitation services at a Spinal Cord Injury Model System center and exhibited discernible neurological deficits.

We studied women enrolled in NSCID who received follow-up interviews from 2000 to 2013, when NSCID collected pregnancy data, and were aged

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18–49 years when interviewed. These 1907 women accounted for 3054 interviews.

Variable definitions

NSCID recorded whether women were hospitalized during the 12 months prior to their interview as a result of uncomplicated childbirth or complications of pregnancy, childbirth and the puerperium. This is the only information NSCID gathered relating to pregnancy; despite its limitations described below, it serves as our binary pregnancy indicator. For convenience, we refer to this indicator as 'current pregnancy.'

Information on sociodemographic characteristics, SCI etiology and primary bladder management method is obtained during the initial post-injury hospitalization and updated at follow-up. SCI level and injury completeness are assessed at discharge from the initial hospitalization using the International Standards for Neurological Classification of Spinal Cord Injury.[9] For analysis, we grouped participants into one of the three categories: (i) tetraplegia with American Spinal Injury Association Impairment Scale (AIS) A, B or C (Tetra ABC); (ii) paraplegia with AIS A, B or C (Para ABC); and (iii) AIS D.

At follow-up interviews, NSCID asks participants to rate their pain over the past 4 weeks as 0 ('no pain') to 10 ('pain so severe (they) cannot stand it'). Subjective health is measured by the following question: 'In general, would you say that your health is excellent, very good, good, fair or poor?' NSCID uses the motor component of the Functional Independence Measure (FIM) to quantify activity limitations by assessing performance in four areas: self-care, sphincter control, mobility and locomotion. Total motor FIM scores range from 13 (complete dependence) to 91 (complete independence).[10]

We measured community participation using subscales of the Craig Handicap Assessment and Reporting Technique (CHART): physical independence, mobility, occupation and social integration.[11] Each CHART subscale has scores ranging from 0 to 100, with higher scores reflecting greater participation. Because of their skewed distributions, we categorized each CHART subscale into three levels: scores 0–50, 51–75 and 76–100.

NSCID assesses the frequency of depressive symptoms over the past 2 weeks using the first 2 questions from the Patient Health Questionnaire (PHQ-9):[12] (i) Over the last 2 weeks, how often have you been bothered by having little interest or pleasure in doing things? and (ii) Over the last 2 weeks how often have you been bothered by feeling down, depressed or hopeless? To assess subjective overall life satisfaction, NSCID uses the Satisfaction with Life Scale (SWLS).[13] SWLS contains 5 statements, each rated on a 7-point Likert-type scale with responses ranging from 'strongly disagree' to 'strongly agree.' Total scores range from 5 to 35, with higher scores reflecting greater life satisfaction. For analysis, we grouped SWLS scores into 3 categories: 5–14,15–29 and 30–35.

Table 1 Current pregnancy percentages by time period

Time period	*Total* n	*Current pregnancy*	
		n	*%*
Years since spinal cord injury			
1	886	5	0.6
5	663	19	2.9
10	503	17	3.4
15	323	12	3.7
20	285	6	2.1
25	267	1	0.4
30	120	0	—
35	7	0	—
Total	3054	60	2.0
Calendar years of data collection			
2000–2002	482	9	1.9
2003–2005	649	8	1.2
2006–2008	775	20	2.6
2009–2011	709	13	1.8
2012–2013	439	10	2.3
Total	3054	60	2.0

Statistical analysis

We calculated the frequency and percentage of women with current pregnancy during a 12-month period, summarizing across the years elapsed since injury, as well as calendar years. We conducted bivariable analyses with descriptive statistics to examine associations between current pregnancy and sociodemographic attributes, SCI etiology, neurological impairment, physical functioning and psychosocial well being. We used generalized estimating equations to determine the statistical significance of comparisons between pregnant and nonpregnant women. Generalized estimating equations accounts for potential dependence among multiple interviews of the same woman.

We performed multivariable logistic regression with generalized estimating equations modeling to identify factors significantly and independently associated with current pregnancy. We used backward model selection, beginning with a full model that included all variables with $P<0.35$ in the preliminary bivariable analyses and sequentially removing the least significant variable from the model until all variables in the final model reached $P<0.05$.

Statement of ethics

We certify that all applicable institutional and governmental regulations concerning human subject research were followed during the course of this study.

RESULTS

Prevalence of current pregnancy

Across all women, 2.0% reported current pregnancy (that is, experienced hospitalization during the past 12 months for a reason related to pregnancy). This annual prevalence differed significantly by the years elapsed since injury (Table 1), with the highest rate reported at post-injury year 15 (3.7%). Prevalence rates varied slightly by calendar years (Table 1), but these differences did not reach statistical significance ($P=0.42$, Table 2).

Bivariable analyses of factors associated with current pregnancy

Table 2 shows bivariable analysis results. Women with current pregnancy were younger at injury and at interview ($P<0.0001$) compared with nonpregnant women. Compared with nonpregnant women, those reporting current pregnancy were also significantly more likely to be married or living with a significant other, have sport-related SCI, have higher FIM motor scores and greater values for all CHART subscale and SWLS scores. The association between discharge neurological impairment and current pregnancy was marginally significant ($P=0.06$), with more AIS D and Para ABC among currently pregnant than nonpregnant women.

Multivariable analyses of associations with current pregnancy

Multivariable analysis identified six factors significantly and independently associated with current pregnancy (Table 3). The adjusted odds of current pregnancy decreased by 9% for each year increase in age at interview and by 6% for each year increase in age at SCI. Other factors significantly associated with current pregnancy included marital status, FIM motor score and CHART mobility and occupation scales.

DISCUSSION

Using data from a relatively large, national SCI registry, we found that ~2% of women aged 18 to 49 years with SCI report pregnancy within the prior 12 months ('current pregnancy'). This rate is virtually identical to the current pregnancy rate of women in the same age range with chronic physical disabilities, regardless of cause, found in

Table 2 Demographic and disability characteristics by 'current pregnancy'

Characteristics	N = *3054 women*				P-*value*[a]
	Pregnant		*Nonpregnant*		
	n	*(%)*	N	*(%)*	
Total	60	(2.0)	2994	(98.0)	
Hispanic					
Yes	5	(8.5)	261	(8.8)	0.9947
No	54	(91.5)	2709	(91.2)	
Unknown	1		24		
Race					
White	45	(75.0)	2273	(77.7)	0.8389
Black	12	(20.0)	487	(16.6)	
Other	3	(5.0)	166	(5.7)	
Unknown	0		68		
Marital Status					
Married/significant other	40	(66.7)	864	(29.1)	<0.0001
Single	12	(20.0)	1416	(47.8)	
Other	8	(13.3)	685	(23.1)	
Unknown	0		29		
Education					
<High school	6	(10.0)	285	(9.7)	0.3476
High school	25	(41.7)	1488	(50.5)	
College or higher	24	(40.0)	1096	(37.2)	
Other	5	(8.3)	80	(2.7)	
Unknown	0		45		
Employment					
Employed	21	(35.0)	800	(27.2)	0.0897
Unemployed/other	36	(60.0)	1819	(61.7)	
Student/trainee	3	(5.0)	327	(11.1)	
Unknown	0		48		
Etiology					
Vehicular crash	41	(68.3)	1950	(65.2)	0.0353
Violence	5	(8.3)	345	(11.5)	
Sports	9	(15.0)	223	(7.5)	
Falls	2	(3.3)	303	(10.1)	
Other	3	(5.0)	171	(5.7)	
Unknown	0		2		
Injury year					
1972–1985	3	(5.0)	487	(16.3)	0.0009
1986–2000	37	(61.7)	1242	(41.5)	
2001–2012	20	(33.3)	1265	(42.3)	
Years since injury					
1 and 5	24	(40.0)	1525	(50.9)	0.0059
10 and 15	29	(48.3)	797	(26.6)	
20 and more	7	(11.7)	672	(22.4)	
Bladder management					
Indwelling catheter	11	(18.3)	851	(28.9)	0.3052
ICP	24	(40.0)	1222	(41.5)	
Catheter-free	2	(3.3)	49	(1.7)	
Other/none	3	(5.0)	148	(5.0)	
Normal	20	(33.3)	677	(23.0)	
Unknown	0		47		
Self-perceived health					
Excellent	10	(17.0)	414	(14.6)	0.3621
Very good	14	(23.7)	887	(31.3)	
Good	21	(35.6)	958	(33.8)	
Fair	13	(22.0)	462	(16.3)	
Poor	1	(1.7)	117	(4.1)	
Unknown	1		156		
PHQ-9 question 1					
Not at all	35	(60.3)	1592	(56.8)	0.4283
Several days	11	(19.0)	742	(26.5)	
>Half the days	6	(10.3)	207	(7.4)	
Nearly every day	6	(10.3)	261	(9.3)	
Unknown/declined	2		192		
PHQ-9 question 2					
Not at all	34	(58.6)	1556	(55.5)	0.8351
Several days	14	(24.1)	812	(29.0)	
>Half the days	4	(6.9)	181	(6.5)	
Nearly every day	6	(10.3)	255	(9.1)	
Unknown	2		190		
Calendar years					
2000–2002	9	(15.0)	473	(15.8)	0.4167
2003–2005	8	(13.3)	641	(21.4)	
2006–2008	20	(33.3)	755	(25.2)	
2009–2011	13	(21.7)	696	(23.3)	
2012–2013	10	(16.7)	429	(14.3)	
AIS at discharge					
A	27	(46.6)	1493	(51.3)	0.4095
B	5	(8.6)	412	(14.2)	
C	9	(15.5)	367	(12.6)	
D	17	(29.3)	637	(21.9)	
E	0	(0.0)	0	(0.0)	
U	2		85		
Level of injury at discharge					
Paraplegic	35	(60.3)	1541	(52.9)	0.2162
Tetraplegic	23	(39.7)	1375	(47.2)	
Normal	0	(0.0)	0	(0.0)	
Unknown	2		78		
Neurological Category at discharge					
Tetra ABC	12	(20.7)	985	(33.9)	0.0581
Para ABC	29	(50.0)	1287	(44.2)	
D	17	(29.3)	637	(21.9)	
Unknown	2		85		
CHART: physical independence					
0–50	1	(1.7)	508	(17.9)	<0.0001
51–75	4	(6.8)	281	(9.9)	

Table 2 (Continued)

Characteristics	N = *3054 women*				P-*value*[a]
	Pregnant		*Nonpregnant*		
	n	*(%)*	N	*(%)*	
76–100	54	(91.5)	2055	(72.3)	
Unknown	1		150		
CHART: mobility					
0–50	1	(1.8)	488	(17.3)	<0.0001
51–75	16	(28.6)	569	(20.2)	
76–100	39	(69.6)	1767	(62.6)	
Unknown	4		170		
CHART: occupation					
0–50	4	(7.1)	888	(31.7)	<.0001
51–75	4	(7.1)	295	(10.5)	
76–100	48	(85.7)	1620	(57.8)	
Unknown	4		191		
CHART: social integration					
0–50	2	(3.5)	222	(8.0)	0.0368
51–75	2	(3.5)	244	(8.8)	
76–100	53	(93.0)	2308	(83.2)	
Unknown	3		220		
Satisfaction with life					
5–14	7	(12.3)	648	(23.2)	0.0129
15–29	28	(49.1)	1555	(55.8)	
30–35	22	(38.6)	586	(21.0)	
Unknown	3		205		
Current age, mean (s.d.)	31.2	(6.7)	35.7	(9.1)	<0.0001
Age at injury, mean (s.d.)	21.3	(5.5)	25.8	(9.0)	<0.0001
FIM motor, mean (s.d.)	78.0	(17.0)	65.2	(24.7)	<0.0001
Unknown	9		388		
Pain severity mean (s.d.)	3.9	(3.2)	4.4	(3.0)	0.2279
Unknown	1		180		

Abbreviations: AIS, American Spinal Injury Association Impairment Scale; CHART, Craig Handicap Assessment and Reporting Technique; FIM, functional independence measure; ICP, intermittent catheterization program; PHQ, patient health questionnaire.
[a]Obtained from bivariable generalized estimating equations analysis (PROC GENMOD modeling the probability that pregnancy = 1 (yes)); unknown excluded.

Table 3 Association of demographic and disability characteristics with current pregnancy

Characteristics	*Adjusted odds ratio*[a]	*95% confidence interval*	P-*value*
Current age (year)	0.91	(0.88, 0.95)	<0.0001
Age at injury (year)	0.94	(0.91, 0.98)	0.004
Marital status			
Married/significant other	1.00	Reference	<0.0001
Single	0.11	(0.05, 0.26)	
Other	0.37	(0.15, 0.89)	
FIM motor	1.02	(1.00, 1.04)	0.027
CHART mobility			
0–50	1.00	Reference	0.015
51–75	6.77	(0.83, 54.88)	
76–100	1.91	(0.24, 15.14)	
CHART occupation			
0–50	1.00	Reference	0.031
51–75	2.36	(0.59, 9.39)	
76–100	2.98	(1.06, 8.38)	

Abbreviations: CHART, Craig Handicap Assessment and Reporting Technique; FIM, functional independence measure.
[a]Adjusted odds ratios from multivariable logistic regression.

the US nationally representative National Health Interview Survey (NHIS).[14] Although this 2% current pregnancy rate is lower than the 3.8% for nondisabled women in NHIS data,[14] after adjusting for age differences, current pregnancy rates were similar among reproductive-aged women with and without chronic mobility impairments in the NHIS analyses. More information is needed about pregnancy experiences and outcomes to help inform women with SCI seeking childbearing and the clinicians providing their care.

Although SCI is generally considered not to affect the ability of women to conceive, no evidence has conclusively proven this assertion. Our study found physical and non-physical factors that were statistically significantly associated with women being currently pregnant. However, our 2% current pregnancy rate was lower than that in other albeit smaller investigations examining pregnancy among women with SCI. One impediment in comparing results across studies is the differences in how pregnancy is identified and the time frame used. For example, examining cross-sectional 'current' pregnancy is different from looking at lifetime prevalence. In one study, researchers interviewed 128 women with SCI about their sociodemographic information, SCI specifics and medical and reproductive histories.[3] About 8% reported current or previous pregnancies; pregnancy rates were statistically significantly higher among women who sustained SCI at younger ages. Another investigation identified women aged 18–40 years with SCI from two Florida databases and solicited their participation in a survey about their reproductive attitudes and experiences.[4] Out of 133 women who responded, 114 with SCI met the inclusion criteria (the study authors did not report information about their number of initial contacts, hence response rates are unclear). Of these women, 44% indicated that they wanted to become pregnant since injury, and 36% successfully conceived. Women who gave birth after SCI were significantly younger at injury than those who did not.

As noted above, NSCID offers the substantial benefits of relatively large size and national reach. However, our 'current pregnancy' indicator has important limitations. We created this variable from information about all hospitalizations for uncomplicated and complicated pregnancy-related events within 12 months prior to women's follow-up interviews. In the 13 years of data analyzed here, only 60 women responded affirmatively at 1 year post SCI or at time intervals representing multiples of 5 years post injury. This means that there were 4-year gaps in coverage of time between interviews during which women could have had pregnancy-related events without reporting them. This makes it likely that overall lifetime pregnancy rates among NSCID women participants are higher than the 2% reported here.

In addition, our measure of current pregnancy encompasses a range of pregnancy-related circumstances, and it provides no information about whether the women actually gave birth. NSCID does not gather data on miscarriages, complications of pregnancy or birth outcomes (for example, premature or term births, cesarean deliveries). In particular, NSCID does not identify first-time pregnancies, whether women have difficulty conceiving, or whether they use assisted

reproductive technology to become pregnant. Furthermore, NSCID does not collect information on pregnancy experiences before SCI for its woman participants.

Despite these shortcomings—and thus the need to confirm our findings with future research—this study offers insight into the characteristics of women with SCI who become pregnant. As women who sustain traumatic SCI are overall a reproductively young population, these insights can help inform pre-conception planning and obstetrical care. Clinicians who provide any aspect of reproductive health care must recognize the distinctive conditions associated with women's SCI and their ramifications for the pregnancy and *post partum* state.

SCI can cause neurological, physical, physiological or psychosocial secondary conditions that directly influence pregnancy at various points along its course. In addition, the adapting female reproductive system during pregnancy may impose direct or indirect consequences on the expression of neurological or musculoskeletal impairments, as well as psychological health (for example, *post partum* depression). Consideration of influences from both directions could affect women's decisions or the ability to become pregnant and her pre-conception care needs. Although our findings do not provide specific guidance about these interacting considerations for women with SCI contemplating pregnancy, these results offer insights that should be investigated in future research.

Our findings suggest that, in this population, two broad sets of interrelated factors could influence pregnancy outcomes: considerations relating to the SCI disability; and consequences relating to age. Disability-related factors include physical, physiological and psychosocial effects of SCI, encompassing women's degrees of functioning and psychological adjustments. Age-related factors include determinants of fertility and thus conception and pregnancy rates, which also affect nondisabled women.

In our study, women with SCI who were currently pregnant self-reported better functional abilities (higher discharge FIM scores) than their nonpregnant counterparts. This indicates that women who became pregnant had better functional abilities with feeding, grooming, bathing, dressing upper and lower body, toileting, bladder and bowel control, transferring (to and from bed, chair, toilet, tub or shower), locomotion and stair climbing. Furthermore, the higher-functioning neurological impairment rating (AIS D and Para ABC) statistically corroborates the association of greater functional abilities with being pregnant.

However, during pregnancy, women's functional status may be affected physiologically by secondary medical conditions caused by her growing fetus, including perhaps exacerbating existing impairments. Depending on the level of injury, varying degrees of pulmonary dysfunction occur following SCI. As the gravid uterus enlarges, its pressure on the diaphragm may further compromise lung vital capacity, precipating poor oxygenation, aggravating fatigue and limiting mobility. Development of pressure ulcers, lower extremity edema, weight gain, urological complications, gastrointestinal dysfunction, postural hypotension and autonomic dysreflexia can occur among women with SCI during pregnancy.[15,16] These conditions can negatively affect women's functional abilities during pregnancy and possibly *post partum*.

In our study, as noted above, women who reported current pregnancy had higher FIM scores and less impaired neurological categories. These discharge outcome measures often improve 1 to 2 years post injury.[17] As NSCID participants were interviewed 1 to 35 years post SCI, the cohort of currently pregnant women may actually have better functional status than indicated by their FIM scores. This would be reflected in the CHART physical independence, mobility and occupation scores, which were also significantly greater for these women.

Psychological consequences may discourage women from seeking pregnancy after SCI and thus result in lower pregnancy rates. We found higher SWLS values among women from NSCID reporting current pregnancy. The literature offers conflicting findings about whether women with SCI experience more anxiety and fear regarding pregnancy and caring for a child than do nondisabled women. Seemingly paradoxically, one study involving 114 women with SCI found that women who became pregnant were statistically significantly more likely to report fears of pregnancy or worries about child rearing than were nonpregnant women with SCI.[4] It appears that the pregnant women did not allow their heightened anxieties to determine their pregnancy decisions.[4] A qualitative study involving in-depth interviews with women with SCI about their attitudes concerning childbirth and parenting identified several themes, including: perceptions that childbirth is unique and positive; the need for person-centered care and control during obstetrical care; and the critical importance of taking a biopsychosocial framework when working with pregnant women with SCI.[18]

Finally, although a complete literature review is beyond our scope here, it is clear that much remains to be learned about the physical, physiological and psychosocial interrelationship of pregnancy and SCI. Factors associated with reproductive system aging and how this affects women with SCI have never been examined. However, these factors may be critical in considering conception and pregnancy among women with SCI. Other important issues involve the potential impact of delayed childbearing among women with SCI and implications for their pre-conception and prenatal care. Educating women with SCI about their choices—being open about what is currently known and not known about pregnancy among women with SCI—is essential when working with women to maximize the likelihood of safe pregnancies and healthy outcomes for mother and child.

CONFLICT OF INTEREST

LII and YC are supported by the research grant. ABJM declares no conflict of interest.

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DATA ARCHIVING

There were no data to deposit.

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