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Consequences of Interstitial Cystitis/Bladder Pain Symptoms on Women's Work Participation and Income: Results from a National Household Sample

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Abstract

Purpose—To describe differences in work participation and income by bladder symptom impact and comorbidities among women with interstitial cystitis/bladder pain syndrome (IC/BPS).

Materials and Methods—Cross-sectional data from2767 respondents under age 65 identified with IC/BPS symptoms analyzed. The data are from the RAND Interstitial Cystitis Epidemiology (RICE) survey and include retrospective self-reports of IC/BPS impact, severity, years since onset, and related comorbidities (depressive symptomology, number of conditions), work participation and income, and personal characteristics. Multiple regressions predicted five current work outcomes: works now, kept from working by pain, missed work days, days worked when bothered by symptoms, and real income change since symptom onset.

Results—Controlling for work status at symptom onset and personal characteristics, greater bladder symptom impact predicted greater likelihood of not now working, kept more days from working by pain, missed more work days, and working more days with symptoms. More depressive symptomology and greater number of co-morbidities predicted reduced work participation. Women experienced no growth in real income since symptom onset. Measures of symptom severity were not associated with any of the economic outcomes.

Conclusions—Greater IC/BPS symptom impact, depressive symptomology, and count of comorbidities (but not symptom severity) were each associated with less work participation and leveling of women's long-term earnings. Management of bladder symptom impact on non-work-related activities and depressive symptomology may improve women's work outcomes.

Keywords

Interstitial cystitis/bladder pain syndrome; probability sample; employment

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Chronic pain syndromes have economic costs. Prior research documents that the direct medical costs for women seeking treatment for interstitial cystitis/bladder pain syndrome (IC/BPS) are twice those for women not diagnosed with IC/BPS[1,2]. Prior work also establishes high economic costs through work loss during the first year following diagnosis.[1–3].

Prior research provides an incomplete picture of the economic burden to women themselves for two reasons. First, the focus on tertiary care clinical samples fails to represent the potentially much larger number of women with undiagnosed and untreated IC/BPS symptoms [4,5]. Second, prior studies do not collect information on work measures prior to onset, so they are unable to estimate the longer term economic costs.

Population-based data with information collected about current and past health and working status and earnings from the RAND Interstitial Cystitis Epidemiology (RICE) survey are used to estimate the relationship between IC/BPS health-related measures and change in women's work participation and income. The study describes consequences to work participation and income associated with the burden of IC/BPS, and the gains to these outcomes that might be achieved with improved clinical and psychosocial management of IC/BPS -related pain symptoms and the reduction in its impact on quality of life and comorbidities.

Methods

Study Design

As described elsewhere[6], the RICE study first screened by telephone survey 146,231 households across the United States in 2007–2009. Second, in each household identified as having one or more women with IC/BPS symptoms, one woman was interviewed. The percent women currently working drops markedly between ages 64 and 65 at the time of the interview (N=2,767), so we restrict the sample to women under 65 years. Population weights derived from screening data were applied.

All predictor and outcome measures are self-reported.

Predictors

Socio-demographic predictor variables were age, race/ethnicity, education, current marital status, living arrangements, and number of lifetime births. Method of renumeration reflects working conditions.[7] Hourly versus non -hourly wages are a predictor of working part-time and part-year, working in a blue collar occupation, and working fewer hours per week. Analyses included a control variable for the units in which earnings were reported (hourly, weekly, monthly or annually).

Six IC/BPS-related health measures were considered. The RAND Bladder Symptom Impact scale (BSI-6) measures the impact of bladder symptoms on quality of life across six areas: interest in life, energy level, moods, feelings of self-worth, social life, and ability to carry out home responsibilities (α=.90 in full RICE sample) [8]. A higher score indicates greater impact on quality of life. Two IC/BPS symptom severity measures were considered: the Interstitial Cystitis Symptom Index (ICSI; α=.85[9]) and Problem Index (ICPI; α=0.90[9]), which assess the presence and degree of IC/BPS symptoms and their associated distress, respectively[9]. Additional measures included years since symptom onset, depressive symptomology, and count of comorbidities. Number of years since onset was calculated from currently reported age and year and age at onset. Depressive symptomology was derived from the Patient Health Questionnaire eight-item (PHQ-8) scale (α=0.83)[10], with a

higher score indicating more depressive symptoms.[10] Number of chronic conditions (listed in Table 1 footnote) respondents self-reported as ever been diagnosed with were summed.

Outcomes

Current work status was determined by the response to the question: "In the past month, were you working for pay at all?" Women who were not currently working were asked if they were kept from working by bladder problems or pelvic pain. Women who worked currently were asked the number of work days missed in the past month because of bladder problems or pelvic pain and the number of days worked when bothered a great deal by their symptoms in the past month. Women who worked for pay were asked about number of hours worked per week and earnings. All earnings were annualized [11] and converted to 2008 dollars. Earnings were bottom-coded so that earnings <50% of the HHS federal poverty level were set to50% ($5200 in 2008). Bottom-coding is used when values below that threshold might be unduly influenced by outliers[12]. An ordered measure of change in income ratio of current to initial earnings with five levels was constructed (see Table 2).

Imputation

Rates of missingness were low (<8%). Cases missing both employment status and earnings when symptoms began were excluded. Simple (mean) imputation of missing predictors was done for cases with missing living arrangements, marital status, and number of children ever born. Missing employment status when symptoms started was imputed from own earnings when symptoms began (if present). When current income was missing, responses provided at the first screening stage were used. When that response was missing, median imputation for all women who reported income in the same unit (e.g., hour, week, month, or year) was used.

Statistical Analysis

First, the characteristics of the sample overall and by work status at onset were summarized. Two sets of multiple regression models were estimated for the subsample of women who worked at onset. The first set of 30 (five outcomes times six IC/BPS-related health measures) included as predictor variables each of the socio-demographic predictor variables and one of each of the six IC/BPS-related health measures. The second (and final) set of five models retained only IC/BPS-related health measures that were statistically significant ($p<0.05$) in at least one of the first set of regression models. Analyses used SAS software, version 9.2.

Logistic regression was used to predict dichotomous outcomes, ordered logistic regression to predict ordered categorical outcomes, and zero-inflated Poisson regression to predict count variables. In sensitivity analyses, imputed cases were excluded.

To illustrate the work effect of insufficiently managed IC/BPS pain and symptoms, results from the regression models described above are presented as "predictive margins" at the (a) 10^{th}percentile on BSI-6 and PHQ-8 and (b) the 90^{th}percentile of these same measures, holding the distribution of all other respondent covariates constant across groups. For non-linear measures such as probabilities or number of days missed, predictive margins can be

used to illustrate expected difference in the outcome associated with changing two predictors in isolation. Differences between these two groups in these covariate -adjusted means and proportions were calculated to determine the amount of difference in these outcomes for women with severe versus mild symptom severity as measured by the BSI-6 and PHQ-8, but who are otherwise similar.

RESULTS

Table 1 presents respondents' demographics. Compared with women who were not working at onset, women who were initially working were older (43 years versus 40 years, $p<0.05$), had fewer years since symptom onset(11 versus 16 years, $p<0.05$), and slightly less depressive symptomology (7.6 versus 8.5, $p<0.05$), but were otherwise similar.

Current Work Participation and Income

At the time of the interview, 42% of women did not work, 18% worked part-time and 40% worked full-time. Of those not currently working, 11% reported that they were kept from working by bladder problems or pelvic pain and 6%of women who worked part -time said IC/BPS pain or symptoms kept them from working full -time. Women missed about one half day of work in past month due to IC/BPS and worked eight days while in pain. The median annualized income (in 2008 dollars) was approximately $29,800, similar to median earnings ($31,500) for US women aged 35 –44[13].

There is little evidence of change in annualized earnings between onset and interview (an average of 13 years): median income at onset (in 2008 inflation-adjusted dollars), $29,900, is nearly indistinguishable from their current median income; about an equal proportion of women reported a small change in income, as reported a moderate or large decrease or moderate or large increase. Median weekly earnings for US women aged 25–34 in 1998 was $595 (in 2008 dollars) compared with $682 for women aged 35–44 in 2008, corresponding to a 15% increase in earnings[13,14] over 10 years. In contrast, there is no evidence that the real earnings of women in the IC/BPS sample grew over a 13 year (on average) interval.

Women working at onset were more likely to be working full -time now compared with women who were not working at onset (47% versus 29%). Women who did not work at onset but were working now missed more days of work in the past month because of pain or symptoms than women who worked at onset (0.7 days versus 0.5 days, $p<0.05$).

Work Status and Income Consequences among Women Who Worked at Symptom Onset

The first series of multiple regression models (one per economic outcome) served to screen ICSI and ICPI from the second models because they were not independently related to any of the five economic outcomes (results not shown). All socio-demographic variables and BSI-6, years since onset, PHQ-8, and comorbidity count were each included in the final model.

Table 3 presents the final models predicting current work status, if bladder problems or pelvic pain kept them from working, and income change. All models control for the full set of socio-demographic characteristics (coefficients not shown). More education ($p<0.05$) is

associated with increased odds of currently working and an increase in income ratio ($p<0.05$). Older age significantly predicts more missed days of work ($p<0.001$), more days worked when bothered by pain or symptoms ($p<0.001$) and decrease in income ratio ($p<0.01$). "Other" race/ethnicity is significantly related to more days worked when bothered by symptoms or pain ($p<0.01$).

The standardized odds ratios are the amount by which the odds of an outcome are changed by a one standard deviation change in the predictor. For example, each one standard deviation change in BSI-6 is positively associated with nearly triple the odds of being kept from working (OR=2.86, $p<0.001$). Joint significance tests confirm that the health measures are jointly related to currently working and kept from working ($p<0.0001$ for each), but are not significantly related to the change in income ratio ($p=0.356$).

Table 4 presents the standardized odds ratios (OR) and the standardized incidence rate ratios (IRR) of each health measure from the zero-inflated Poisson models. For illustration's sake, each one standard deviation increase in BSI-6 is associated with nearly doubling of odds of missing any days of work ($p<0.001$) and, among those who missed any days of work, it was associated with nearly 50% increase in the number of missed days.

Looking across Tables 3 and 4, BSI-6 is significantly related to four of five work participation and income outcomes among women who worked at onset —in most cases, the direction of the association is such that greater symptom impact and worse health is positively associated with work loss or working while in pain. Years since onset, PHQ-8, and comorbidity count each predict currently working and days worked when bothered (Table 3). The pattern of relationships between years since onset and work participation outcomes is mixed. Years since onset is associated with lower odds of working now (OR=0.61, $p<0.001$), whereas amongst those who work, years since onset is associated with reduced incidence of days worked when bothered by pain (IRR=0.90, $p<0.05$).

Sensitivity analysis (not reported here) found that all results are robust to the exclusion of imputed cases.

Three work participation outcomes (works now, number days missed work, and days worked when bothered) were compared for women at the 90thpercentile on the BSI-6 and PHQ-8 with women at the 10th percentile of each. The predicted probability of working now is nearly doubled among for women in the 10 percentile on BSI -6 and PHQ-8 scales compared with women at the 90thpercentile of both (43 % vs. 79%, respectively). Similarly large differences are observed for number of days missed work (2.5 days vs. 0.1 days) and number of days worked while in pain (14 days vs. 6 days).

DISCUSSION

Overall, 42% of women did not work; 10% of whom say they did not work because of IC/BPS pain or bladder symptoms. On average, in the past month employed women missed ½ day of work due to pain or symptoms and worked while in pain 8 days. Bladder impact on life activities is associated with four of five work measures, controlling for other IC/BPS-related health measures and socio-demographic characteristics. More depressive

symptomology and comorbidities are also associated with reduced work productivity. This suggests IC/BPS substantially and adversely effects work productivity.

IC/BPS can reduce ability to fulfill work obligations[1]: IC/BPS patients sometimes feel a constant need to urinate, which requires constant access to bathrooms. Repeated waking during the night can lead to chronic fatigue and affect job performance and slow wage increases if the employer perceives the woman is less productive. Women may be unwilling to accept jobs with more responsibility if the jobs decrease flexibility and increase stress. Depressive symptomology in combination with pain is strongly linked to disability and work loss among women[15]. Future research will want to collect information on the timing of pain and symptoms, depression, and economic outcomes to examine if depression is a key mediator in the relationship between IC/BPS and work productivity.

There is little association between measures of symptom impact and related health measures with change in earnings since onset. If employment opportunities are consistent with IC/BPS, IC/BPS may have muted effects on earnings. Accommodations can range from allowing flexible use of leave time (for medical appointments) to locating an employee with IC/BPS near a bathroom or allowing working remotely. However, there were virtually no changes in real earnings in these women from early 30s (when the average woman in our sample report symptom onset) to early 40s, in stark contrast to the 15% gain in earnings in age cohorts of women in the United States during a comparable period[13,14]). Women with IC/BPS symptoms, regardless of symptom impact, may be falling behind in earnings compared with their peers. Our other work loss measures may be more contemporaneously related to current health IC/BPS symptoms whereas income change may reflect longer cumulative health effects which are less will captured by our health measures.

Our study has several limitations. Although retrospective reports on work status at symptom onset are available, the data are observational, thereby limiting our ability to infer causality. Work environment characteristics are unavailable, so identifying what types of employers are better able to accommodate IC/BPS was not possible. The study's field period started around the beginning of the "Great Recession" (December 2007), possibly influencing the overall level of work participation; however, this timing is unlikely to have biased the estimated relationships between predictor and outcome variables since larger economic context would have affected all study participants.

IC/BPS and concomitant depressive symptomology are strongly related to women's work loss—specifically, working in pain, reduced productivity, and decreased quality of life in the work domain.

CONCLUSION

Bladder symptom impact on life activities is the most consistent predictor of work outcomes, followed by comorbidity count and depressive symptomology. There were no independent effects of measures of presence and degree of symptoms and their associated distress. Functional status and effective coping mechanisms may matter more for work participation and productivity than symptoms. Clinical management of IC/BPS should

involve providing patients with the psychosocial tools to improve coping and self-management of their condition, as well as focusing on effective pain management and treatment of urinary symptoms.

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Table 1

Socio-demographic characteristics of women <65 years with IC/BPS, by work status when symptoms started

	All Respondents	Work Status at Onset #	
Socio-Demographic Characteristics	**N=2767**	**Working N=1637**	**Not working N=1121**
Age at interview (range 18–64 years), mean (SE)	42 (0.31)	43 (0.39)	40*** (0.49)
Race/Ethnicity, %			
White	72.5	72.5	72.5
Black	10.8	11.3	10.1
Hispanic	11.7	11.6	11.7
Other	4.9	4.5	5.4
Education, %			*
No College	35.6	33.6	38.5
Some College	35.7	35.5	38.9
College Plus	28.7	30.9	25.6
Lives alone, %	9.3	9.4	9.0
Currently married, %	65.0	65.7	63.9
Number of births (range 0–5), mean (SE)	2.0 (0.03)	2.0 (0.04)	2.1 (0.06)
Bladder symptom impact (BSI- 6) (range 0–7), mean (SE)	1.7 (0.04)	1.7 (0.05)	1.8 (0.06)
Years since symptom onset (range 1–60), mean (SE)	13 (0.25)	11 (0.26)	16*** (0.45)
Raw PHQ-8 (range 0–24), mean (SE)	8.0 (0.14)	7.6 (0.18)	8.5** (0.22)
Number of co-morbidities& (range 0–9), mean (SE)	1.5 (0.04)	1.5 (0.05)	1.6 (0.06)

Missing eight cases with missing work status at onset.

* indicates *p*-value <.05 for test of difference from women who worked at symptom onset;

** $p < .01$;

*** $p < .001$. &Co-morbidities are (1) fibromyalgia, (2) chronic fatigue syndrome or Epstein-Barr syndrome, (3) irritable bowel syndrome or spastic colon, (4) chronic sinusitis, (5) chronic migraine, (6) heart disease or heart attacks, (7) chronic lung disease/emphysema, (8) diabetes, (9) cancer other than skin cancer or bladder cancer, (10) arthritis or rheumatism, (11) vulvodynia or vulvar vestibulitis, and (12) overactive bladder. All percents and means are weighted. IC/BPS = Interstitial cystitis/bladder pain syndrome.

Table 2

Work participation and income outcomes of women <65 years with IC/BPS symptoms, overall and by work status at symptom onset

Work Participation and Income Outcomes	All Respondents	Work Status at Onset[#]	
		Working	Not Working
Current work status, % (n=2767)			***
Full-time (>=35 hours/week)	39.7	46.9	29.2
Part-time (<35 hours/week)	18.2	18.8	17.4
Not working	42.1	34.3	53.4
Kept from working by bladder problems or pelvic pain, % (n=1833)	10.5	10.2	11.1
Kept from working full time by bladder problems/pelvic pain, % (N=536)	5.5	4.7	7.2
Number of work days missed (range 0–20), mean (SE) (N=1451)	0.6 (0.05)	0.5 (0.06)	0.7* (0.73)
Number of days worked when bothered (range 0–20), mean (SE) (N=1451)	7.9 (0.23)	8.1 (0.28)	7.4 (0.42)
Current annual personal earnings (2008 dollars), median (SE) (N=1451)	$29,600 ($1100)	$29,800 ($800)	$25,900** ($1500)
Change in income ratio (2008 dollars), % (N=1067)			
Large decrease (<=66.7%)	--	17.7	--
Moderate decrease (>66.7–<90%)	--	11.9	--
Small change (90–110%)	--	41.0	--
Moderate increase (>110–<150%)	--	13.3	--
Large increase (>=150%)	--	16.0	--

[#]Missing eight cases with missing work status at onset.

*indicates p-value <.05 for test of difference from women who worked at symptom onset;

** $p < .01$;

*** $p < .001$. All percents and means are weighted. IC/BPS = Interstitial cystitis/bladder pain syndrome.

Table 3

Standardized odds ratios from logistic and ordinal regression models of work participation and income outcomes of women who worked at symptom onset

	Works now (N=1628)			Kept from working (N=618)			Change in income ratio (N=987)		
IC/BPS-related health measures	**Standardized OR**	**95% CI**		**Standardized OR**	**95% CI**		**Standardized OR**	**95% CI**	
BSI-6[#]	0.69***	0.59	0.82	2.86***	2.20	3.72	1.07	0.86	1.34
Years since symptom onset	0.61***	0.51	0.72	1.06	0.79	1.44	0.99	0.79	1.25
PHQ-8	0.72***	0.61	0.85	1.05	0.78	1.36	0.84	0.68	1.05
Count of co-morbidities	0.61***	0.52	0.72	1.11	0.87	1.43	0.95	0.76	1.18

[#]Models also include age, race, education, lives alone, currently married, number of births, and units in which income reported in when symptoms started.

* indicates p-value <.05 for test of difference from women who worked at symptom onset;

** $p < .01$;

*** $p < .001$

Table 4

Standardized odds ratios and standardized incidence rate ratios from zero-inflated Poisson models of work participation outcomes for women who worked at onset

	Number of days missed from work in past month (N=1010)							Number of days worked in past month when bothered by symptoms (N=1010)						
	Any (vs. 0)			(If any) number			Joint test	Any (vs. 0)			(If any), number			Joint test
IC/BPS-related health measures	**Standardized OR**	**95% CI**		**Standardized IRR**	**95% CI**		***P***	**Standardized OR**	**95% CI**		**Standardized IRR**	**95% CI**		***P***
BSI-6[#]	1.90***	1.38	2.61	1.54**	1.14	2.06	0.00	2.22***	1.43	3.46	1.18***	1.10	1.27	0.00
Years since symptom onset	0.96	0.64	1.42	0.75	0.55	1.04	0.12	0.81	0.61	1.09	0.90*	0.83	0.98	0.02
PHQ-8	0.94	0.68	1.31	1.37**	1.10	1.72	0.02	1.21	0.86	1.71	1.07	0.99	1.14	0.13
Count of co- morbidities	1.56**	1.15	2.11	0.91	0.77	1.07	0.02	1.29	0.92	1.79	1.10**	1.03	1.17	0.01

[#]Models also include age, race, education, lives alone, currently married, number of births, and units in which income reported in when symptoms started.

*indicates p-value <.05 for test of difference from women who worked at symptom onset;

** $p < .01$;

*** $p < .001$.