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Demographic Differences and Disparities in the Misdiagnosis of Interstitial Cystitis/Bladder Pain Syndrome in a National Cohort of VA Patients

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Abstract

Objectives: **To explore** the association between misdiagnosis of IC/BPS and demographics. Interstitial cystitis/bladder pain syndrome (IC/BPS) is associated with significant diagnostic uncertainty, resulting in frequent misdiagnosis. There is little known about the potential impact of key demographic factors on IC/BPS prevalence and rates of misdiagnosis.

Methods: All in the VA system between 1999–2016 were identified by ICD-9/10 codes for IC/BPS (595.1/N30.10) (n=9,503). ICD code accuracy for true IC/BPS was assessed by in-depth chart abstraction to determine actual IC/BPS presence by strict criteria. Associations were explored between rates of misdiagnosis and demographics.

Results: IC/BPS criteria were met in only 651 (48.8%) of the 1,334 charts with an ICD code for IC/BPS reviewed in depth. There were no differences in the misdiagnosis rate by race (p=0.27) or by ethnicity (p=0.97), after adjusting for differences in age and gender. In IC/BPS-confirmed cases, female patients were diagnosed at a younger age than males (41.9 vs. 58.2 years, p<0.001). Black and Hispanic patients were diagnosed at a younger age compared to White (41.9 vs. 50.2 years, p<0.001) and non-Hispanic patients, respectively (41.1 vs. 49.1 years, p=0.002).

Conclusion: There was a high rate of misdiagnosis of IC/BPS overall, with only 48.8% of patients with an ICD code for IC/BPS meeting diagnostic criteria. There were no significant associations between diagnostic accuracy and race/ethnicity. Black and Hispanic patients were more likely to receive a diagnosis of IC/BPS at a younger age, suggesting there may be differing natural histories of IC/BPS between racial/ethnic groups.

DISCLAIMER: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Introduction:

The burden of interstitial cystitis/painful bladder syndrome (IC/BPS) is immense in both human and financial terms. According to the Society of Urodynamics, Female Pelvic Medicine and Urogenital Reconstruction (SUFU), IC/BPS is defined as “an unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms of more than six weeks duration, in the absence of infection or other identifiable causes” (1–6). As there is no definite diagnostic test for IC/BPS, it is essentially diagnosed based on exclusion. This results in frequent misdiagnosis, as symptoms of IC/BPS frequently overlap with other lower urinary tract conditions such as overactive bladder syndrome (OAB), vulvodynia and endometriosis in women, and chronic prostatitis and chronic orchalgia in men (7–8). Estimates of the overall prevalence of IC/BPS thus fluctuate widely. For example, one prior study in a managed care population found a prevalence ranging from 0.045% to 0.197% for women and between 0.008% and 0.041% for men (7). Prevalence of IC/BPS was estimated as part of the Urologic Diseases in America Project (8). Based on National Health and Nutrition Examination Survey III data, it was reported that the prevalence of IC/BPS was found to be 0.85% for women and 0.06% for men (8). Thus, based upon administrative claims data, contemporary IC estimates give a ~20-fold range for women and an ~8-fold range for men with a total prevalence <1% (8).

In many fields such as surgery (10–15), oncology (13–18), urology (16,19,20), and medicine (21–22) there have been multiple publications on the impact of socioeconomic and racial factors on outcomes, with many of these studies reporting disparities in outcomes. Although IC/BPS has classically been considered a disease found predominantly in White female patients, there is a surprising dearth in the literature regarding racial and demographic disparities and the diagnosis and management of IC/BPS. Further, the findings in existing literature vary when it comes to this topic.

The RAND IC Epidemiology Study (RICE), funded by the National Institute of Diabetes and Digestive and Kidney Diseases, surveyed 100,000+ US households and estimated an IC/BPS prevalence of 2.7%−6.5% in US women over the age of 18 (23). The RICE study also analyzed a small sample of men (6,072 households) and found that the prevalence of IC/BPS in men ranged from 1.9%−4.2% (24). Prevalence rates of IC were similarly estimated from 2002–2005 by the Boston Area Community Health (BACH) survey. In that study, 5,506 men and women ages 30 to 79, who were residents in the Boston metropolitan area, were surveyed. The overall prevalence of symptoms suggestive of IC/BPS “was 2% (1.3% in men and 2.6% in women) with increased prevalence in middle-aged adults and those of lower socioeconomic status” (25). Prior studies such as data from the BACH trial reported that males with IC/BPS tended to be older, compared to females (25). One study by Clemens et al. exploring BACH survey results suggested that the prevalence of IC/BPS in non-White patients may be higher than expected, possibly equal to that of White patients (26).

Given the variation in reported demographics in literature, we aimed in this this study to explore the rates of and reasons for misdiagnosis of IC/BPS in a large national cohort of patients, focusing on demographic disparities.

Methods:

After obtaining IRB approval, the Veterans Affairs Informatics and Computing Infrastructure (VINCI) was used to identify all patients in the VA system between 1999 and 2016 with at least 2 clinic visits in the past 2 years with an ICD-9/10 code for IC/BPS (n=9,503) (595.1/N30.10). We predicted that there would also be patients who would meet criteria for IC/BPS with chart abstraction, despite not having an ICD code for the condition. Therefore, we additionally identified patients who had an ICD-9/10 code for an IC/BPS-"like" condition (conditions that could frequently be misdiagnosed as IC/BPS. These ICD/BPS-"like" conditions (n=133,834) included prostatitis (men only), vagismus, vulvar vestibulitis, vulvodynia (women only), and dyspareunia (men and women). All other patients were considered controls (n=5,203,529). Patients with an IC/BPS-"like" condition must not have had a code for IC/BPS, and the controls had neither IC/BPS nor IC/BPS-"like" codes.

A key advantage of the VINCI database is that is combines the scope of a large population-based administrative database with in-depth chart abstraction. Our goal was to perform in-depth chart abstraction on the patients identified to determine who truly met diagnostic criteria for IC/BPS as well as to determine the rates of misdiagnosis. However, given the large number of patients we expected to have these codes (as well as the very large pool of controls) coupled with limited resources, we elected to obtain large representative random samples of these patients to analyze in depth.

We aimed to perform in depth chart review in at least 1,500 patients with a code for IC/BPS or an IC/BPS-"like" condition. We ensured that at least 80% (n=1,200) came from the pool of subjects with an actual ICD-9/10 code of IC/BPS (i.e. assessing for overdiagnosis) and 20% (n=300) came from the pool of subjects with an ICD-9/10 code for an IC/BPS-"like" condition. This sample size of at least 1,500 patients was decided based on our prior work in which 40% of patients overall (varying 28%−50% between gender and racial/ethnic groups) with a diagnosis code for IC/BPS were able to be shown to meet actual IC/BPS criteria (i.e. there was sufficient data from in depth chart review and patient met criteria after in-depth chart review) (27). As 25% of this group was non-White or Hispanic, a sample of 1,500 would provide an 80% power to detect a 10% difference in proportion of true IC/BPS (with subgroups of 375). We additionally aimed to review the charts of at least 500 controls as prior pilot data had revealed that 0.5% of these patients were found to meet IC/BPS criteria with chart review. The cases were selected with a random number generator. Since the VA patient population consists of more male than female patients, these samples were gender balanced.

Criteria for a correct/actual diagnosis of IC/BPS were met if at least one of the following conditions was met:

1. Two visits (in the VA system) complaining of an unpleasant bladder-centric sensation in the absence of a positive urine culture at least 6 weeks apart.
2. One visit complaining of bladder-centric pain/unpleasant bladder-centric sensation and a second visit complaining of "likely" IC/BPS-related pain in the absence of a positive urine culture at least 6 weeks apart (both at the VA). We defined "likely" IC/BPS-related pain as pain that could be due to IC/BPS but without a specific complaint of bladder-centric pain or bladder tenderness on exam. Symptoms of "likely" IC/BPS include dysuria, pelvic pain, chronic lower abdominal pain, and dyspareunia.
3. A history of bladder pain and/or a history of IC/BPS (in the VA or other system) with one additional visit complaining of bladder-centric pain in the absence of a positive urine culture.

Cases where it was not possible to determine if true IC/BPS criteria were met under chart review were classified as equivocal (these cases were considered IC/BPS + for our analysis. A sensitivity analysis treating these patients as IC- did not change our findings). Cases were excluded if a competing diagnosis was present that would make assessment of true IC/BPS difficult (Figure 1). If chart abstraction revealed that a patient did not meet criteria for IC/BPS, their actual diagnosis or reason for not meeting the criteria was determined.

We collected demographic information including age, gender, race (White, Black, Asian/Pacific Islander, Native American, and Other) and ethnicity (Hispanic-Latino or non Hispanic-Latino). Differences in these demographics were assessed between patients who had an ICD code for IC/BPS, an IC/BPS-"like" code and controls. Rates of misdiagnosis (specifically rates of patients with IC/BPS codes who were IC.BPS negative with chart review) were compared between demographic groups.

Statistical Methods:

Differences between groups were tested initially with univariate analysis using ANOVA, Chi-square, or simple linear or logistic regression. Multivariate analysis was performed with logistic regression models. In all testing, post-hoc Tukey's test was used to adjust for multiple comparisons. Differences were considered significant if the two-tailed p value was less than 0.05.

Results:

Of the 5,346,866 active VA patients identified, 9,503 had a code for IC/BPS and 133,834 had a code for an IC/BPS-"like" conditions. Of the 1,857, 388, and 919 randomly-sampled charts for in-depth abstraction from the IC/BPS ICD code present, IC/BPS ICD "like" code present, and controls, 523 (28.2%), 116 (29.9%), and 241 (26.2%) cases were excluded, respectively (Figure 1). True IC/BPS criteria were met in 651 (48.8%) of the 1,334 remaining cases with an ICD code for IC/BPS. Only 11 (4.0%) of the 272 cases with IC/BPS-"like" codes met diagnostic criteria for IC/BPS. Of the 678 controls that were reviewed in depth, 4 (0.6%) met diagnostic criteria for IC/BPS (Figure 1).

Control cases were on average younger (52.6 years ± 16.3 (Standard Deviation)) and had a higher BMI (30.2 ± 6.6) than cases with an ICD code for IC/BPS (55.6 years ± 15.8, 28.7 ± 5.7, p<0.001) or an IC/BPS "like" code (55.4 years ± 16.4, 28.2 ± 5.7, p<0.001) (Table 1). Patients with an ICD code for IC/BPS were more commonly female than controls (56% vs. 44%, p<0.001). There was a significant difference overall in the racial make-up between cohorts in general (Table 1). Specifically, patients with a code for IC/BPS were more commonly White as compared to controls (75% vs. 70%, p=0.024). There were only 36 and 12 patients in the control and IC/BPS "like" group, respectively, where IC/BPS was confirmed or equivocal with in depth chart review.

On initial analysis of patients who had a diagnosis code of IC/BPS (simple logistic regression) there was no difference in the misdiagnosis rate by race (p=0.273) or by ethnicity (p=0.972). Even after adjusting for the significant differences in age and gender with multivariate analysis, there was still is no difference in the misdiagnosis rate by race (p=0.102) or ethnicity (p=0.719) (Table 2). The reason for misdiagnosis (Figure 1) was also not significantly different by race or ethnicity (p=0.398, p=0.281). However, among the IC/BPS-confirmed cases, we observed that Black confirmed cases were diagnosed at a younger age compared to White patients (41.9 vs. 50.2 years, p<0.001). Similarly, Hispanic IC/BPS confirmed cases were diagnosed at a younger age compared to non-Hispanic cases (41.1 vs. 49.1 years, p=0.002). In IC/BPS confirmed patients, female patients were diagnosed at a younger age than male patients (41.9 vs. 58.2 years, p<0.001) (Table 3). There were, however, differences in rates of misdiagnosis by age and gender. Specifically, of the 579 male patients with an ICD code for IC/BPS, 214 were misdiagnosed (37.0%) compared to 233 of the 755 female patients with IC/BPS being misdiagnosed (30.9%, p=0.019) (Table 2). Patients who were misdiagnosed were also older, on average (57.5 vs. 54.6 years, p=0.002) (Table 2).

Although adjusted sampling was performed to allow for prevalence estimates by race, the data here suggests the prevalence of IC/BPS among minorities to be lower than Whites (Table 1). Blacks were less likely to have a confirmed case of IC/BPS than Whites (p=0.004), after adjusting for gender and age (Table 2). Specifically, while Black patients made up 25% of the patients in the control cohort (Table 1), they only comprised 20% (Table 2) of the patients with a true IC/BPS diagnosis (given the misdiagnosis rate was not different by race, this suggest the overall prevalence of true IC/BPS is lower in Blacks.) The same was true for Asian patients (1% of confirmed IC/BPS patients, and 3% of controls, p=0.015). However, the data did not suggest a difference in prevalence of IC/BPS by ethnicity, as there was not a significant difference in the proportion of patients who were and were not of Hispanic-Latino ethnicity in the cohort of true IC/BPS patients and controls (True IC/BPS cohort 6% Hispanic vs. 8% in the Control group, p=0.247).

With multivariate analysis, there were interactions between age of diagnosis, ethnicity (p=0.0006), and race (p<0.0001). Hispanic males were significantly younger than non-Hispanic males at diagnosis (42.8 vs. 58.6 years, p<0.0001), and overall, non-Hispanic males were significantly older than all other subgroups (Supplementary Table 1). Black males were diagnosed at significantly younger ages than White males (41.9 vs. 52.3 years, p<0.0001). White males were significantly older at diagnosis, compared to both

Black (52.3 vs. 38.6 years, p<0.0001) and White females (52.3 vs. 40.8 years, p<0.0001) (Supplementary Table 1).

Discussion:

In this study we report a high rate of misdiagnosis of IC/BPS, with only 48.8% of patients with an ICD code for IC/BPS actually meeting diagnostic criteria. Even including equivocal cases as true IC/BPS cases, the misdiagnosis rate was still 33.5%. Our data here suggests no difference in the misdiagnosis rate by patient race or ethnicity. There were, however, differences in rates of misdiagnosis by age and gender. Specifically, male patients and patients of older age were more frequently misdiagnosed. This is a very interesting finding considering that IC/BPS is classically considered a diagnosis predominantly affecting white women of younger age (26). In our study we did find that rates of misdiagnosis were the lowest in the groups where IC/BPS were more common (i.e. younger females). It is important to note, however, that these rates of misdiagnosis we report are cases where an IC/BPS code was assigned, but rigorous IC/BPS meet criteria are not met. Thus, the higher misdiagnosis rate observed in older male patients may be related to the fact that practitioners may not be as familiar with the presentation of IC/BPS in these patients (nor as familiar with potential competing differential diagnoses).

Our data also suggest that the prevalence of IC/BPS among minorities is lower (as compared to White patients). We also observed interesting differences in the demographics at time of diagnosis: Black and Hispanic confirmed cases were diagnosed at a younger age compared to White and non-Hispanic patients.

We found that women were diagnosed at a younger age (41.9 years) than men (58.2 years). This is consistent with previous literature (7, 25, 26). In a study of a managed care population by Clemens et al. (7), the highest prevalence of IC/BPS was in women aged 41–45 (266 per 100,000), while the highest male prevalence rates were observed in the oldest age groups (66–80 years). Similarly, Link et al. reported (BACH Trial) the prevalence of symptoms suggestive of BPS was highest for men aged 60–69 and women aged 40–49 (25).

There is little existing literature specifically exploring the differences and disparities in the diagnosis of IC/BPS by race and ethnicity. Although IC/BPS has classically been a disease attributed to White females, the fact that 24% of the confirmed IC/BPS cases in our study were non-White or Hispanic, suggests that IC/BPS may be more common in other demographic groups than initially believed. Another study utilizing the Boston Area Community Health (BACH) survey, an epidemiologic study of 5,506 randomly selected adults aged 30–79 of three racial/ethnic groups (Black, Hispanic, White) reported prevalence estimates of symptoms suggestive of IC/BPS of 2.32%, 3.09%, and 1.63% for Black, Hispanic and White persons (p-value ns), respectively (25).

Despite the strengths of this study, there are limitations that must be discussed. First, our data comes from the VA databases, and thus our findings may not be completely applicable to the population at large. Fortunately, this limitation is likely mitigated by the fact that the

VA databases represent a large heterogenous population. Several studies utilizing the VA databases have produced results comparable to those generated by other datasets (28–33). Another limitation is that the VA datasets represent a single payer system, thus limiting our ability to comment on the impact of socioeconomic disparities. This is an area deserving of future study given the likely covariation of race and ethnicity and socioeconomic factors. This is an area deserving of further study.

Despite its limitations, this study has many notable strengths. We applied a novel methodology where the scope of a large population-based dataset is combined with individual chart review. This approach addresses key difficulties in studying IC/BPS. Specifically, IC/BPS is notoriously difficult to diagnose given that it is essentially a diagnosis of exclusion. Studies based exclusively on survey data or administrative data may fail to rule out differential conditions that present with similar symptoms to IC/BPS. For example, estimates of IC/BPS from the BACH data are based on “symptoms suggestive of” IC/BPS (25).

In conclusion, the study we present here represents, to the extent of our knowledge, the largest and most rigorous assessment of the rates of misdiagnosis of IC/BPS among different demographics groups. Our data here suggests no difference in the misdiagnosis rate by patient race or ethnicity. There were, however, differences in rates of misdiagnosis by age and gender. Specifically, male patients and patients of older age were more frequently misdiagnosed. These findings are of clinical value as they highlight the common pitfalls that occur in diagnosing IC/BPS. Specifically, although IC/BPS has been classically regarded as a disease predominantly affecting White women, our data here suggests that while it is still most common in this demographic group, it may be more prevalent in other demographic groups than classically appreciated. Further, although IC/BPS may be more common than previously suspected in non-White patients, the age at presentation is different in these patients, with Black and Hispanic patients diagnosed at a younger age. This suggests that there are possibly differing natural histories of IC/BPS between racial or ethnic groups (or differing physician diagnostic patterns). Our findings that IC/BPS is more commonly misdiagnosed in men and patients of older age is a very important finding worth of study. We hypothesize that it is the knowledge that IC/BPS is a condition that predominately affects young women that drives this higher rate of misdiagnosis. Future directions should explore specific differences in presenting symptoms and treatment effectiveness among patients with varying demographics.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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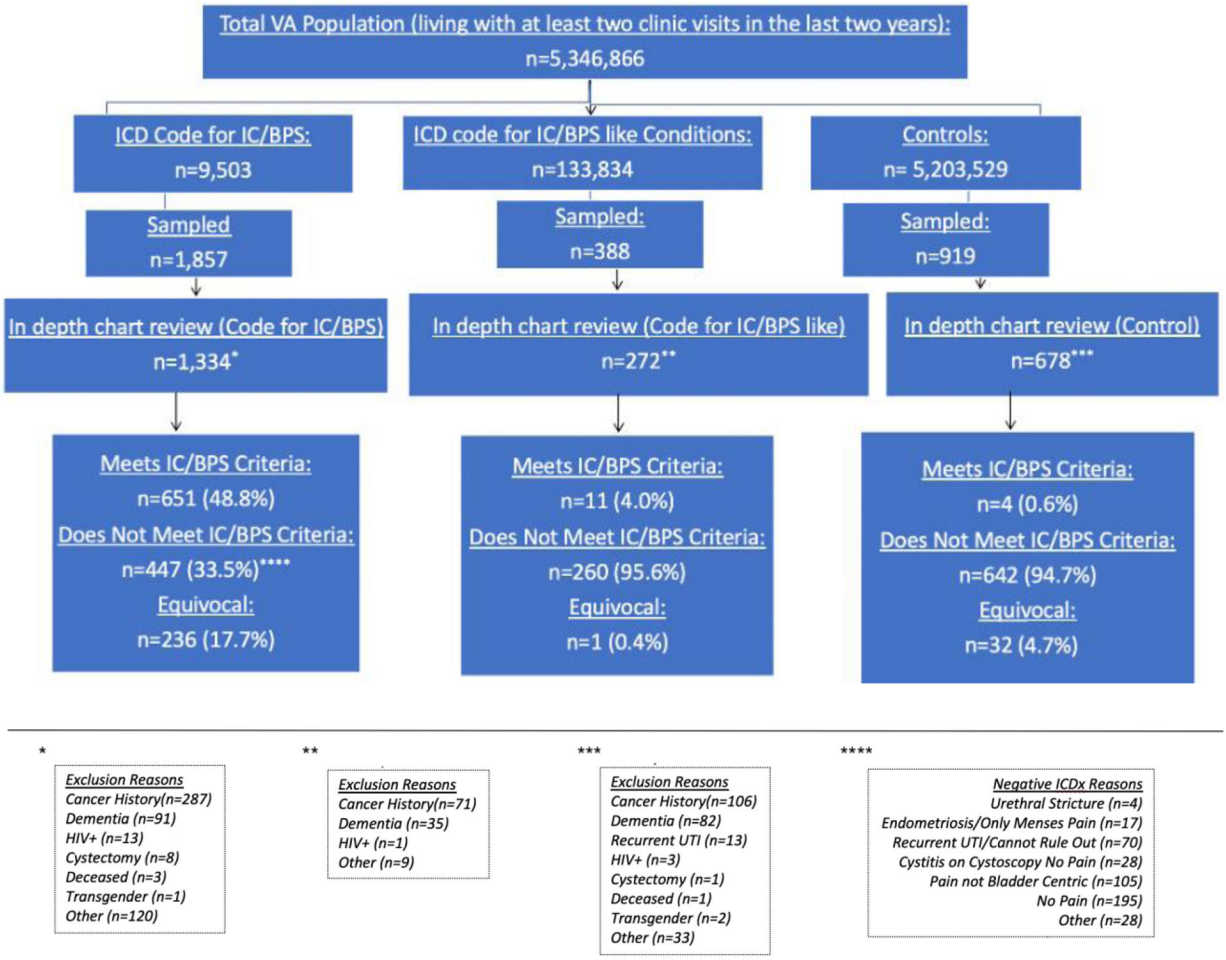

Figure 1:
Consort Diagram of Rates of Misdiagnosis of IC/BPS in a Large National Cohort

Table 1:

Rates and Demographic Characteristics of Patients with an ICD code of IC/BPS and IC/BPS-"like" Condition and Controls

	IC/BPS+ (n=1,334)		IC/BPS-Like (n=272)		Controls (n=678)		p-value***
Age at Abstraction	55.6 ± 15.8 *		55.4 ± 16.4		52.6 ± 16.3		<0.001
Sex **							
Male	579	43%	112	41%	377	56%	<0.001
Female	755	56%	160	58%	301	44%	
Race							
White	1000	75%	198	73%	471	70%	
Black	279	21%	51	19%	171	25%	
Asian/Pacific Islander	21	2%	11	4%	20	3%	0.003
Native American	15	1%	2	1%	7	1%	
Other/Unknown	19	1%	10	4%	9	1%	
Ethnicity							
Hispanic or Latino	84	6%	14	5%	53	8%	0.252
Not Hispanic or Latino	1250	94%	258	95%	625	92%	
BMI	28.7 ± 5.7		28.2 ± 5.7		30.2 ± 6.6		<0.001
IC+ Confirmed	651	49%	11	4%	4	0.6%	
IC+ Equivocal	236	18%	1	0%	32	4.7%	
IC Negative	447	34%	260	96%	678	100%	

* Standard Deviation

** Females were over selected to achieve a 1:1 balance. However due to exclusion criteria, the ratio became unbalanced.

*** Differences between groups tested with ANOVA (continuous) or Chi-square (discreet)

Table 2:

Demographic Disparities of IC/BPS Confirmed and Misdiagnosed Cases

	IC/BPS Confirmed (n=887)		IC/BPS Misdiagnosed (n=447)		p-value[a]	p-value[b]
Age Abstraction	54.6 ± 16.1		57.5 ± 15.1		0.002	
Age at dx	48.6 ± 15.4		50.5 ± 14.9		0.038	
BMI	28.6 ± 5.6		29.0 ± 6.0		0.279	
Gender						
Male	365	41%	214	48%	0.019	
Female	522	59%	233	52%		
Race						
White	678	76%	322	72%		
Black	175	20%	104	23%		
Asian/Pacific Islander	11	1%	10	2%	0.273	0.102
Native American	9	1%	6	1%		
Other/Unknown	14	2%	5	1%		
Ethnicity						
Hispanic or Latino	56	6%	28	6%	0.972	0.719
Not Hispanic or Latino	831	94%	419	94%		

*Assuming that equivocal cases are true IC/BPS cases. Analysis considering these cases as IC/BPS negative did not change our findings

p-values computed with (a) simple logistic regression or (b) multivariable logistic regression including age of diagnosis, gender, race, and ethnicity.

Table 3:

Differences in Age of Diagnosis of IC/BPS by Gender and Race/Ethnicity*

	Age of Diagnosis(n=887)	p-value[a]
Gender		
Male	58.2 ± 15.2	<0.001
Female	41.9 ± 11.6	
Race		
White	50.2 ± 16.1	
Black	41.9 ± 10.6	
Asian/PacIsle	50.8 ± 16.1	<0.001
NatAm	47.2 ± 13.3	
Other/Unk	54.9 ± 15.5	
Ethnicity		
Hispanic or Latino	41.1 ± 13.8	0.002
Not Hispanic or Latino	49.1 ± 15.4	
Race/Ethnicity		
White Non-Hispanic	51.5 ± 15.9	
Black Non-Hispanic	43.5 ± 13.5	<0.001
White Hispanic	40.3 ± 13.5	
Other/Unk	50.0 ± 13.8	
Not Hispanic or Latino	49.1 ± 15.4	

p-values computed with (a) simple linear regression.

*In patients with a confirmed or equivocal diagnosis of IC/BPS with chart review