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# Interstitial Cystitis and Painful Bladder Syndrome

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**Purpose:** We quantified the burden of interstitial cystitis/painful bladder syndrome on the health care system in the United States.

**Materials and Methods:** The analytical methods used to generate these results were described previously. Interstitial cystitis was defined based on International Classification of Diseases, 9th revision code 595.1 (interstitial cystitis). For painful bladder syndrome we used the definition International Classification of Diseases, 9th revision code 788.41 (urinary frequency) with code 625.8 (other specified symptoms associated with female genital organs) or 625.9 (unspecified symptoms associated with female genital organs).

**Results:** Between 1992 and 2001 there was a 2-fold increase in the rate of hospital outpatient visits and a 3-fold increase in the rate of physician office visits related to interstitial cystitis. The annualized rate was 102 office visits per 100,000 population. Ambulatory surgery for interstitial cystitis decreased. A diagnosis of interstitial cystitis was associated with a 2-fold increase in direct medical costs. Between 1994 and 2000 annual national expenditures for interstitial cystitis were stable at \$37 million but annual costs for painful bladder syndrome increased from \$481 million to \$750 million.

**Conclusions:** Although interstitial cystitis accounts for a small percent of health care visits, its economic burden is substantial. Because of misdiagnosis, the true burden of interstitial cystitis/painful bladder syndrome on the health care system in the United States is probably underestimated in administrative data that rely only on physician coding to identify the disorder. The greatest part of the disease burden is likely not captured in this economic analysis.

*Key Words:* bladder; cystitis, interstitial; pain; health services research; cost and cost analysis

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Interstitial cystitis and PBS are enigmatic chronic conditions characterized by frequent urination and bladder pain. Because no objective marker exists for IC/PBS, the exact prevalence of the disorder is not currently known. The prevalence of a formal physician diagnosis of IC is relatively low at approximately 200/100,000 population<sup>1</sup> but the prevalence of IC-like symptoms is much higher at approximately 5,000/100,000.<sup>2,3</sup> The prevalence of symptomatic but undiagnosed IC/PBS is not known and it will be difficult to determine, given the lack of an objective marker. Patients with IC/PBS experience considerable morbidity during their lives, especially during the most productive years for work and family life.<sup>4</sup> We used a compilation of large national databases to review trends in health care use, including inpatient and outpatient arenas, and summarize cost data related to IC/PBS in the United States. Although the data presented focus on the direct medical costs of IC, patients are equally if not more affected by loss of work opportunities, effects on relationships and overall decreased quality of life.

## MATERIALS AND METHODS

The analytical methods used to generate these results were described previously.<sup>5,6</sup> Given the ongoing evolution of the definitions of IC and PBS, we created code based criteria for PBS for the analyses presented. This approach should be considered exploratory because the term PBS was not in use before 2002. Each table indicates the code based definition that was used.

## RESULTS

### Trends in Health Care Resource Use

The data sets used have several limitations that are evident when one attempts to study health care resource use for IC. 1) The most robust information is limited to elderly individuals, eg those in the Medicare and Veterans Affairs databases. Since IC occurs in individuals of all ages, only a minority of affected individuals are represented. 2) Because the data sets that provide information about individuals of all ages typically include smaller patient populations, the estimates obtained are often imprecise. 3) The identification of individuals with IC is based on a physician coded diagnosis of the condition (ICD-9 code 595.1). As a result, individuals with undiagnosed IC, those who are not accurately coded and those who are misdiagnosed or without access to medical care are not included in the estimates. These limi-

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tations should be kept in mind when reviewing the resource use data presented.

**Inpatient care.** Most care provided for patients with IC occurs in the outpatient setting. However, inpatient admissions may occasionally be required for pain control or in conjunction with certain treatments, eg cystectomy and pain control following bladder hydrodistention. According to data from the Healthcare Cost and Utilization Project the national rate of inpatient hospitalization for IC in 2000 was 0.8/100,000 population for a total of 1,519 admissions. The rate in women was 1.3/100,000 and in men it was 0.2/100,000. Virtually all those admitted were white. These values appeared stable across the years analyzed (1994, 1995, 1998 and 2000). The hospitalization rate increased with age, which may reflect medical comorbidities. Alternatively older patients with more chronic symptoms may undergo more aggressive treatments that require hospitalization. The preponderance of admissions occurred in urban settings, perhaps indicating that more invasive treatment was rendered at urban referral centers.

**Outpatient care.** Table 1 lists the rates of hospital outpatient visits for Medicare beneficiaries with a diagnosis of IC for 1992, 1995, 1998 and 2001. During this period the rate increased from 3.7/100,000 population in 1992 to 7.9/100,000 in 2001. This increase was evident in men and women, although the increase was more dramatic in men.

Physician office visit rates for patients with IC were determined from the National Ambulatory Medical Care Survey, from which data were reported on the even years 1992 to 2000 (table 2). Based on data on these 5 years combined the annualized rate was 102 office visits per 100,000 population. Small cell size precluded analysis of trends with time. Virtually all visits were by white women in metropolitan areas and the rate was higher in patients older than 55 years. Additional analysis showed that 92% of the visits were to urologists.

Table 3 lists data on physician office visits for IC as a primary or secondary diagnosis in individuals who had commercial insurance through United Healthcare in 1994, 1996, 1998, 2000 and 2002. During this interval the rate of visits with IC as any diagnosis increased from 11/100,000 to 31/100,000 population. The rate in women increased from 19/100,000 to 58/100,000. In three-fourths of the visits IC was listed as the primary diagnosis.

Table 4 shows the rates of physician office visits for Medicare beneficiaries with a diagnosis of IC in 1992, 1995, 1998 and 2001. During this period the rate increased from 79/100,000 population in 1992 to 112/100,000 in 2001. These findings are consistent with the increase in Medicare hospital outpatient visits for IC, as discussed. The yearly number of office visits per individual diagnosed with IC was stable at 2.0 throughout the periods examined (table 5). Comparison of the number of visits by specialty indicated that 80% of the visits were to urologists (data not shown).

**Ambulatory surgery visits.** Data from the National Survey of Ambulatory Surgery from 1994 to 1996 showed an annualized visit rate of 12/100,000 population yearly. In women the rate was 22/100,000 (table 6). Table 7 shows corresponding rates for individuals who had United Healthcare health insurance for the even years 1994 to 2000. Dur-

TABLE 1. Hospital outpatient visits by Medicare beneficiaries with IC as primary diagnosis

	1992			1995			1998			2001		
	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate
Totals all ages	1,300	3.7 (2.8-4.6)	3.7	1,240	3.5 (2.6-4.4)	3.5	1,760	5.2 (4.2-6.3)	5.2	2,800	7.9 (6.6-9.3)	7.9
Total younger than 65	440	7.9 (4.6-11)		280	4.6 (2.2-7.0)		500	8.0 (4.9-11)		1,180	17 (12-21)	
Total 65 or older	860	2.9 (2.1-3.8)		960	3.3 (2.4-4.2)		1,260	4.6 (3.5-5.8)		1,620	5.7 (4.5-7.0)	
Sex:												
M	80	0.5 (0.0-1.1)	0.4	80	0.5 (0.0-1.0)	0.5	220	1.5 (0.6-2.4)	1.5	520	3.4 (2.1-4.7)	2.9
F	1,220	6.1 (4.6-7.6)	6.2	1,160	5.7 (4.3-7.2)	5.7	1,540	8.1 (6.3-9.9)	8.0	2,280	11 (9.4-14)	12
Race/ethnicity:												
White	1,240	4.2 (3.2-5.2)	4.2	1,180	3.9 (2.9-4.9)	3.9	1,620	5.7 (4.5-6.9)	5.6	2,160	7.2 (5.9-8.6)	7.1
Black	40	1.3 (0.0-3.2)	1.3	60	1.9 (0.0-4.0)	1.9	100	3.2 (0.4-6.1)	3.2	560	16 (10-22)	17
Asian	Not available	Not available	Not available	0	0	0	0	0	0	0	0	0
Hispanic	Not available	Not available	Not available	0	0	0	40	5.7 (0.0-14)	5.7	40	5.0 (0.0-12)	5.0
North American native	Not available	Not available	Not available	0	0	0	0	0	0	0	0	0
Region:												
Midwest	400	4.6 (2.6-6.6)	3.7	580	6.4 (4.1-8.8)	6.4	360	4.2 (2.2-6.1)	4.2	600	6.8 (4.4-9.3)	6.6
Northeast	200	2.6 (1.0-4.2)	2.9	180	2.3 (0.8-3.9)	2.3	560	8.4 (5.3-12)	8.7	1,100	16 (12-20)	16
South	300	2.5 (1.2-3.7)	2.5	280	2.2 (1.0-3.4)	2.0	480	3.9 (2.3-5.4)	4.2	720	5.4 (3.7-7.2)	5.3
West	400	7.3 (4.1-10)	8.4	200	3.9 (1.5-6.3)	3.9	360	7.3 (3.9-11)	5.7	380	7.0 (3.9-10)	7.4

ICD-9 code 595.1, unweighted counts multiplied by 20 to arrive at values, rate per 100,000 Medicare beneficiaries in the same demographic stratum, age adjusted rate adjusted to the United States Census derived age distribution of the year under analysis and individuals of other races, unknown race and ethnicity, and other region included in the total (counts less than 600 should be interpreted with caution) (source: Centers for Medicare and Medicaid Services, 5% Carrier and Outpatient Files, 1992, 1995, 1998 and 2001).

TABLE 2. Physician office visits for IC as any diagnosis

	1992-2000		
	Count	Rate (95% CI)	Annualized Rate
Totals	974,129	508 (337-679)	102
Age:			
Younger than 55	593,574	428 (235-621)	86
55 or Older	380,555	718 (359-1,077)	144
White	956,335	662 (435-889)	132
Female sex	922,936	922 (597-1,247)	184
MSA:*			
MSA	837,017	571 (375-766)	114
NonMSA	*	*	*

ICD-9 code 595.1, rate per 100,000 based on 1992 to 2000 population estimates from Current Population Survey, CPS Utilities, Unicon Research Corp, for relevant demographic categories of adult civilian noninstitutionalized population in the United States, individuals of other races, and with missing or unavailable race and ethnicity, and missing MSA included in the total and values for male sex do not meet reliability or precision standard (counts may not sum to total due to rounding) (source: National Ambulatory Medical Care Survey, 1992, 1994, 1996, 1998 and 2000).  
\* Value does not meet reliability or precision standard.

ing this period there was a slight increase in the rate of IC as any diagnosis from 12/100,000 to 19/100,000 population and an increase in women from 23/100,000 to 34/100,000. Of these visits 89% listed IC as the primary diagnosis. For Medicare beneficiaries the rate of ambulatory visits remained stable at 12/100,000 to 13/100,000 between 1992 and 2001, including 17/100,000 to 20/100,000 women. These rates do not reflect additional outpatient procedures performed in the office or hospital setting.

**Medicare data on physician office procedures.** Table 8 shows trends in office procedures for IC in Medicare beneficiaries in 1992, 1995, 1998 and 2001. Data are presented for bladder irrigation/instillation (CPT code 51700) and cystoscopy (CPT code 52000). Additional procedures examined included cystoscopy with hydrodistention for IC (CPT codes 52260 and 52265) and cystoscopy with urethral dilation

(CPT code 52281) but there were too few counts for these conditions to generate reliable data. The rates presented reflect the number of procedures per 100,000 individuals with a diagnosis of IC. The bladder instillation rate was relatively stable at 50,000/100,000 to 70,000/100,000 population and it was lower in the Northeast than in other regions. There was a slight but consistent decrease in the cystoscopy rate with time from 9,091/100,000 population in 1992 to 7,515/100,000 in 2001. Small cell size precluded an analysis of cystoscopy use by region. Table 9 shows cumulative procedure rates by summing the data from 1992, 1995, 1998 and 2001. The annualized rate for bladder irrigation was 63,319/100,000 population, the annualized rate for cystoscopy was 8,574/100,000, the annualized rate for cystoscopy with hydrodistention was 1,043/100,000 and the annualized rate for cystoscopy with urethral dilation was 1,021/100,000. The relatively low rate for cystoscopy with hydrodistention may reflect the greater age of this population. It is possible that many of these individuals underwent hydrodistention at a younger age at diagnosis. It is surprising that cystoscopy was less commonly used in men since other diseases that could produce the same symptoms are more common in men, such as bladder cancer, bladder stones and bladder outlet obstruction. The reason for this discrepancy is not clear.

**PBS**

The data used previously in this chapter to assess health care resource use for IC were limited to patients with a coded physician diagnosis (ICD-9 code 595.1). To assess the health care resource use for PBS we used another definition for the condition, that is individuals with ICD-9 code 788.41 (urinary frequency) along with ICD-9 code 625.8 (other specified symptoms associated with female genital organs) or 625.9 (unspecified symptoms associated with female genital organs). This definition is based on coded symptoms rather than a label of IC and it may provide a more accurate

TABLE 3. Physician outpatient visits by individuals with IC who had commercial health insurance

	1994		1996		1998		2000		2002	
	Count	Rate	Count	Rate	Count	Rate	Count	Rate	Count	Rate
Primary diagnosis	64	9	92	8	250	14	336	17	386	22
Age:										
18-24	3	*	4	*	13	*	23	*	29	*
25-34	16	*	15	*	55	13	76	17	76	21
35-44	26	*	39	12	81	16	93	17	100	21
45-54	10	*	22	*	59	15	98	21	109	26
55-64	8	*	11	*	36	18	35	14	61	26
65 or Older	1	*	1	*	6	*	11	*	11	*
Sex:										
F	59	15	84	15	232	26	308	30	359	41
M	5	*	8	*	18	*	30	3.0	27	*
Any diagnosis	83	11	122	11	322	18	480	24	546	31
Age:										
18-24	4	*	7	*	14	*	29	*	37	17
25-34	18	*	22	*	69	17	105	24	103	28
35-44	35	16	50	16	106	21	130	23	145	31
45-54	15	*	29	*	8	21	144	30	155	37
55-64	9	*	13	*	41	21	56	23	85	36
65 or Older	2	*	1	*	9	*	16	*	21	*
Sex:										
F	74	19	114	20	293	33	440	43	506	58
M	9	*	8	*	27	*	41	4.1	41	4.7

ICD-9 code 595.1, rate per 100,000 based on member months of enrollment in calendar years for individuals in the same demographic stratum (source: Center for Health Care Policy and Evaluation, 1994, 1996, 1998, 2000 and 2002).  
\* Value does not meet reliability or precision standard.

TABLE 4. Physician office visits by Medicare beneficiaries with IC as primary diagnosis

	1992			1995			1998			2001		
	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate
Totals all ages	27,520	79 (75-83)	79	32,860	93 (88-97)	93	38,600	115 (110-120)	115	39,500	112 (107-117)	112
Total younger than 65	2,240	40 (33-48)		3,640	59 (51-68)		5,280	85 (75-95)		7,540	107 (96-118)	
Total 65 or older	25,280	86 (81-91)		29,220	100 (95-105)		33,320	122 (116-128)		31,960	113 (108-119)	
Race/ethnicity:												
White	25,940	88 (83-93)	88	30,380	100 (95-105)	99	35,220	124 (118-130)	123	35,520	119 (113-124)	118
Black	800	27 (19-35)	24	1,600	50 (39-61)	53	1,640	53 (41-64)	55	2,180	64 (52-76)	65
Asian	Not available	Not available	Not available	40	24 (0.0-57)	12	40	13 (0.0-30)	13	180	38 (13-63)	42
Hispanic	Not available	Not available	Not available	200	50 (19-81)	50	560	80 (50-109)	91	460	58 (34-82)	53
North American native	Not available	Not available	Not available	0			20	37 (0.0-109)	37	40	60 (0.0-142)	60
Sex:												
M	3,360	23 (19-26)	22	3,320	22 (18-25)	23	4,500	31 (27-35)	31	5,460	35 (31-40)	35
F	24,160	121 (114-127)	121	29,540	146 (139-154)	146	34,100	179 (170-187)	179	34,040	171 (163-180)	172
Region:												
Midwest	6,760	77 (69-86)	74	6,980	77 (69-86)	73	7,380	86 (77-94)	85	8,700	99 (90-108)	97
Northeast	3,840	50 (43-57)	50	4,760	62 (54-70)	64	6,300	94 (84-104)	94	6,260	91 (81-101)	91
South	12,280	100 (93-108)	106	15,600	123 (114-131)	125	17,920	145 (135-154)	148	17,360	131 (122-140)	132
West	4,440	81 (70-92)	76	5,360	103 (91-116)	101	6,740	136 (122-151)	128	6,680	124 (110-137)	124

ICD-9 code 595.1, unweighted counts multiplied by 20 to arrive at values, rate per 100,000 Medicare beneficiaries in the same demographic stratum, age adjusted rate adjusted to the United States Census derived age distribution of the year under analysis and individuals of other races, unknown race and ethnicity, and other region included in the totals (counts less than 600 should be interpreted with caution) (source: Centers for Medicare and Medicaid Services, 5% Carrier and Outpatient Files, 1992, 1995, 1998 and 2001).

TABLE 5. Physician office visits by Medicare beneficiaries with IC

	Count	No. Visits/Pt
1992:		
Totals	27,520	2.0
Males	3,300	1.9
Females	24,220	2.0
1995:		
Totals	32,860	2.0
Males	3,320	1.9
Females	29,540	2.0
1998:		
Totals	38,580	2.1
Males	4,500	1.9
Females	34,080	2.1
2001:		
Totals	39,500	1.9
Males	5,460	2.1
Females	34,040	1.9

ICD-9 code 595.1, unweighted counts multiplied by 20 to arrive at values (counts less than 600 should be interpreted with caution) (source: Centers for Medicare and Medicaid Services, 1992, 1995, 1998 and 2001).

assessment of the burden of PBS or undiagnosed IC. We recognize that this definition may include individuals with etiologies other than PBS to explain the symptoms. Furthermore, men with PBS are excluded by definition. In general counts were low for these codes. These limitations should be considered when interpreting the data.

**Outpatient care.** Table 10 shows physician outpatient visits related to PBS in the United Healthcare insured population for 1994 to 2002. The visit rate was 8/100,000 population in 2002 and it appeared to increase during the analyzed periods. PBS was listed as the primary diagnosis in approximately two-thirds of these visits. Age specific analyses could not be performed due to low cell size. The rate of hospital outpatient visits for PBS during this time was negligible.

**Economic Impact**

The economic impact of disease includes direct costs paid to the medical system and indirect costs borne by the individual and society. Direct costs include payments to physicians for inpatient and outpatient care, payments to hospitals for inpatient care, payments for outpatient procedures and tests, and the costs of prescription drugs, among others. Indirect costs include potentially measurable items such as

TABLE 6. Ambulatory surgery visits with IC as any diagnosis

	1994-1996		Av Annualized Rate/Yr
	Count	Rate (95% CI)	
Total	70,224	37 (31-44)	12
Age			
25-34	12,090	30 (17-42)	10
35-44	19,905	48 (28-67)	16
45-54	10,426	34 (18-51)	11
65-74	11,505	64 (43-84)	21
Females	64,231	65 (53-77)	22

ICD-9 code 595.1, rate per 100,000 based on 1994, 1995 and 1996 population estimates from Current Population Survey, CPS Utilities, Unicon Research Corp. for relevant demographic categories of adult civilian non-institutionalized population in the United States, and values for ages 18 to 24, 55 to 64, and 75 years or older, and male sex do not meet reliability or precision standard (counts may not sum to total due to rounding) (source: National Survey of Ambulatory Surgery, 1994, 1995 and 1996).

TABLE 7. Ambulatory surgery visits by individuals with IC who had commercial health insurance

	1994		1996		1998		2000		2002	
	Count	Rate	Count	Rate	Count	Rate	Count	Rate	Count	Rate
	<i>Primary diagnosis</i>									
Totals	86	12	139	12	238	13	319	16	281	16
Age:										
18-24	6	*	11	*	21	*	28	*	27	*
25-34	20	*	27	*	41	10	74	17	50	14
35-44	35	16	45	14	74	15	89	16	78	17
45-54	20	*	38	16	62	16	72	15	81	19
55-64	5	*	16	*	34	17	45	18	37	16
65 or Older	0	*	2	*	7	*	11	*	8	*
Sex:										
F	83	21	190	23	221	25	296	29	261	30
M	3	*	9	*	17	*	23	*	20	*
	<i>Any diagnosis</i>									
Totals	92	12	158	14	285	16	400	20	326	19
Age:										
18-24	6	*	13	*	24	*	33	13	29	*
25-34	20	*	32	12	52	13	92	21	62	17
35-44	38	18	52	16	90	18	107	19	92	20
45-54	23	*	42	17	72	18	92	19	92	22
55-64	5	*	17	*	40	20	59	24	41	17
65 or Older	0	*	2	*	7	*	17	*	10	*
Sex:										
F	88	23	148	26	267	30	368	36	301	34
M	4	*	10	*	18	*	32	3	25	*

ICD-9 code 595.1, rate per 100,000 based on member months of enrollment in calendar years for individuals in the same demographic stratum (source: Center for Health Care Policy and Evaluation, 1994, 1996, 1998, 2000 and 2002).

\* Value does not meet reliability or precision standard.

the consequences of time away from work (borne by the individual, employers, etc) and lost productivity when at work. Disease also has a substantial impact through indirect costs that are more difficult to measure, such as work, education and social opportunities not pursued; general decrements in quality of life; loss of family and social support; and even depression, divorce and (for some patients with IC/PBS) suicide. The databases used in this compendium contain information primarily on direct costs of the disease. This section presents the available data, while also pointing out deficiencies in the data set and areas where indirect costs are particularly important. The definitions used for these analyses are the same as those used in other chapters in the assessment of health care resource use.

**Cost of disease per individual.** Medical and pharmacy claims from 25 large employers for 1.8 million covered lives yielded data that included primary and secondary beneficiaries from 1999 and 2002. Estimated annual expenditures were derived from multivariate models controlled for age, gender, work status (active/retired), median household income based on zip code, urban/rural residence, medical and drug plan characteristics (managed care, deductible and co-insurance/co-payments) and 17 disease conditions, including diabetes, asthma and hypertension.

Although fewer than 0.1% of claims were related to IC, the cost of the disease was significant. In 2002 the mean annual cost associated with IC was \$8,420 vs \$4,169 for those without IC (table 11). When the same analysis was performed to identify patients with PBS, the results were similar, that is \$9,046 for those with PBS vs \$4,650 for those without PBS (table 12). Analysis of specific subgroups revealed certain facts. 1) The cost was disproportionately associated with women. The diagnosis of IC/PBS resulted in costs of almost \$1,750 more per patient for females than for

males. 2) Unlike the costs for other urological conditions such as benign prostatic hyperplasia and urolithiasis, IC/PBS costs were almost identical throughout all geographic regions. This may reflect the limited treatment options, which provide little room for variation in patterns of care. 3) In patients with IC costs appeared to be disproportionately borne by those in the most productive years of life with an extra cost per individual of \$6,712 at ages 35 to 44 years, while extra costs for those 45 to 64 years old were \$4,095. There was no clear cost/age trend in patients with PBS.

Increased medical costs appeared to present a major burden to the health care system with \$2 spent on patients with IC/PBS for every dollar spent on those without the disease. Further investigation is warranted to evaluate the nature and effectiveness of the expenditures, and improve disease management.

**National expenditures on IC/PBS.** In addition to individual costs, we examined trends in national expenditures through a compilation of use data from national surveys and corresponding reimbursement information.<sup>5,6</sup> Data were insufficient to estimate expenditures for PBS. Our discussion is limited to expenditures for IC. National expenditures for IC increased by 29% between 1994 and 2000 to \$66 million (table 13).

## DISCUSSION

Little is known about the economic impact of IC/PBS on patients or the health care system. This evaluation shows that outpatient visits related to IC/PBS are increasing. This may be due to increased awareness of the disorder or to a national increase in the number of patients. The rate of ambulatory surgery visits for IC/PBS decreased, which may

TABLE 8. Bladder irrigation (CPT 51700) and cystourethroscopy (CPT 52000) in physician office setting for Medicare beneficiaries with IC

	1992			1995			1998			2001		
	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate	Count	Rate (95% CI)	Age Adjusted Rate
<b>Bladder irrigation (CPT code 51700):</b>												
Totals	12,620	56,239 (44,404–68,074)		15,940	67,830 (54,040–81,620)		12,840	48,489 (39,494–57,484)		18,140	69,479 (55,575–83,382)	
Males	1,360	39,766 (5,363–74,169)	45,029	2,280	63,687 (8,972–118,402)	67,598	1,500	37,313 (14,438–60,189)	38,816	840	20,000 (7,250–32,750)	19,048
Females	11,260	59,201 (46,663–71,739)	58,254	13,680	68,574 (55,551–81,597)	67,871	11,340	50,490 (40,697–60,283)	50,579	17,300	78,976 (62,639–95,313)	79,250
Midwest	2,960	53,430 (31,894–74,965)	50,903	3,380	58,478 (38,469–78,486)	51,211	2,820	50,357 (32,680–68,035)	49,286	4,280	69,256 (46,617–91,894)	67,961
Northeast	760	17,593 (4,487–30,698)	18,981	1,520	41,989 (19,370–64,608)	40,884	620	14,027 (4,711–23,344)	15,837	700	17,588 (0.0–38,588)	21,106
South	6,960	81,119 (56,521–105,717)	84,382	8,640	86,922 (59,618–114,225)	90,946	7,340	63,937 (47,270–80,604)	63,240	9,520	85,125 (60,390–109,860)	84,409
West	1,940	51,053 (27,373–74,732)	45,789	2,400	60,000 (33,330–86,670)	61,500	2,040	42,678 (23,618–61,738)	43,933	3,620	81,532 (43,559–119,504)	82,432
<b>Cystourethroscopy (CPT code 52000):</b>												
Totals	2,040	9,091 (7,233–10,948)		1,980	8,426 (6,717–10,134)		2,080	7,855 (6,302–9,408)		2,000	7,515 (6,051–8,979)	
Males	140	4,094 (676–7,511)*	4,094	180	5,028 (1,796–8,260)*	4,469	200	4,975 (1,943–8,007)*	5,473	280	6,667 (3,014–10,319)*	5,714
Females	1,900	9,989 (7,889–12,090)	9,989	1,800	9,036 (7,106–10,966)	9,036	1,880	8,370 (6,621–10,120)	8,281	1,720	7,678 (6,078–9,279)	8,044

ICD-9 code 595.1, unweighted counts multiplied by 20 to arrive at values, rate per 100,000 Medicare beneficiaries 65 years or older with IC (as defined by ICD-9 code 595.1 only), age adjusted rate adjusted to 2001 United States Census and individuals of other races, unknown race and ethnicity, and other region included in the total (counts less than 600 should be interpreted with caution) (source: Centers for Medicare and Medicaid Services, 1992, 1995, 1998 and 2001).  
 \* Value does not meet reliability or precision standard.

TABLE 9. Procedure use in physician office setting for Medicare beneficiaries with IC in 1992 to 2001

Group	CPT Code 51700			CPT Code 52000			CPT Codes 52260 + 52265			CPT Code 52281		
	Count	Annualized Rate	Age Adjusted Annualized Rate	Count	Annualized Rate	Age Adjusted Annualized Rate	Count	Annualized Rate	Age Adjusted Annualized Rate	Count	Annualized Rate	Age Adjusted Annualized Rate
Totals:	14,880	63,319		2,015	8,574		245	1,043		240	1,021	
Sex:												
M	1,495	41,760	43,575	200	5,587	5,307	10	279	279	30	838	838
F	13,385	67,194	66,867	1,815	9,111	9,137	235	1,180	1,180	210	1,054	1,029
Race/ethnicity:												
Asian	20	50,000	50,000	5	12,500	12,500	0			0		
Black	395	39,500	41,500	40	4,000	4,500	10	1,000	1,000	5	500	500
Hispanic	30	21,429	25,000	25	17,857	14,286	0			0		
North American native	0			0			0			0		
White	14,085	64,729	64,522	1,895	8,709	8,709	235	1,080	1,020	235	1,080	1,057
Region:												
Midwest	3,360	58,131	55,104	325	5,623	5,536	85	1,471	1,471	15	260	260
Northeast	900	24,862	26,519	280	7,735	7,459	55	1,519	1,381	50	1,381	1,243
South	8,110	81,590	82,847	955	9,608	9,809	65	654	704	140	1,408	1,358
West	2,500	62,500	62,250	420	10,500	10,125	40	1,000	1,000	35	875	875

Based on CPT code 51700 (bladder irrigation, simple, lavage and/or instillation), code 52000 (cystourethroscopy separate procedure), 52260 (cystourethroscopy with dilation of bladder for IC; general or conduction [spinal] anesthesia), 52265 (cystourethroscopy with dilation of bladder for IC, local anesthesia), 52281 (cystourethroscopy with calibration and/or dilation of urethral stricture or stenosis, with or without meatotomy, with or without injection procedure for cystography, male or female), IC ICD-9 code 595.1, unweighted counts multiplied by 20 to arrive at values, rate per 100,000 Medicare beneficiaries 65 years or older in 1995 with IC, age adjusted rate adjusted to 2001 United States Census and individuals of other races, unknown race and ethnicity, and other region included in the total (counts less than 600 should be interpreted with caution) (source: Centers for Medicare and Medicaid Services, 1992, 1995, 1998 and 2001).

TABLE 10. Physician outpatient visits for females with PBS who had commercial health insurance

	1994		1996		1998		2000		2002	
	Count	Rate	Count	Rate	Count	Rate	Count	Rate	Count	Rate
	<i>Primary procedure</i>									
Totals	4	*	19	*	44	5	51	5	52	6
Age:										
18-24	1	*	1	*	7	*	6	*	4	*
25-34	0		9	*	11	*	12	*	8	*
35-44	0		3	*	14	*	18	*	19	*
45-54	2	*	5	*	7	*	11	*	13	*
55-64	1	*	0		4	*	2	*	4	*
65-74	0		1	*	1	*	2	*	3	*
75-84	0		0		0		0		1	*
85 or Older	0		0		0		0		0	
Region:										
Midwest	4	*	15	*	33	8	31	6	33	7
Northeast	0		0		1	*	1	*	3	*
Southeast	0		4	*	7	*	18	*	14	*
West	0		0		3	*	1	*	2	*
	<i>Any procedure</i>									
Totals	5	*	27	*	65	7	79	8	72	8
Age:										
18-24	1	*	1	*	10	*	11	*	6	*
25-34	0		14	*	21	*	17	*	13	*
35-44	1	*	5	*	19	*	28	*	24	*
45-54	2	*	5	*	8	*	17	*	18	*
55-64	1	*	1	*	6	*	4	*	6	*
65-74	0		1	*	1	*	2	*	4	*
75-84	0		0		0		0		1	*
85 or Older	0		0		0		0		0	
Region:										
Midwest	5	*	22	*	51	12	47	10	47	10
Northeast	0		0		1	*	4	*	3	*
Southeast	0		5	*	10	*	24	*	20	*
West	0		0		3	*	4	*	2	*

ICD-9 code 788.41 (urinary frequency) with ICD-9 code 625.8 or 625.9, rate per 100,000 based on member months of enrollment in calendar year for individuals in the same demographic stratum (source: Center for Health Care Policy and Evaluation, 1994, 1996, 1998, 2000 and 2002).

\* Value does not meet reliability or precision standard.

indicate a trend toward a clinical diagnostic approach and away from procedure based diagnosis/therapy. More than 90% of office visits associated with a coded diagnosis of IC were to urologists. It is probable that many more patients with IC/PBS are seen by other physicians and not accurately diagnosed. Therefore, the true burden of IC/PBS on the health care system in the United States is probably underestimated in administrative data that rely only on physician coding to identify the disorder. This analysis attempts to account for this situation by creating a category for PBS for

which no ICD-9 definition exists. The definition encompasses patients with urgency/frequency (788.41) and pelvic pain (625.8 or 625.9). However, these latter codes include various unspecified genital disorders and, therefore, they may overestimate the burden of PBS. It is also true that the specific code for IC (595.1) might be overused by urologists when coding a patient with nonspecific symptoms or it may be underused in the primary care community, where patients may not be evaluated. A new code for PBS would be welcomed along with specific guidelines for using the IC code.

TABLE 11. Estimated annual expenditures for privately insured employees with and without IC medical claim in 2002

	\$ Annual Expenditures/Pt Without IC (477,339 pts)			\$ Annual Expenditures/Pt With IC (244 pts)		
	Medical	Prescription Drugs	Totals	Medical	Prescription Drugs	Totals
All	2,993	1,176	4,169	5,772	2,648	8,420
Age:						
35-44	2,597	1,011	3,608	8,405	1,915	10,320
45-64	3,352	1,341	4,693	5,801	2,987	8,788
Sex:						
M	2,912	1,105	4,017	3,560	2,785	6,345
F	3,109	1,278	4,387	5,996	2,457	8,453
Region:						
Midwest	2,980	1,121	4,101	5,749	2,550	8,299
Northeast	2,806	1,254	4,060	5,414	2,826	8,240
South	3,156	1,153	4,309	6,088	2,570	8,658
West	2,949	1,157	4,106	5,688	2,634	8,322

ICD-9 code 595.1, primary beneficiaries 18 to 64 years old with employer provided insurance who were continuously enrolled in 2002, estimated annual expenditures derived from multivariate models controlled for age, gender, work status (active/retired), median household income based on zip code, urban/rural residence, medical and drug plan characteristics (managed care, deductible and co-insurance/co-payments) and binary indicators for 28 chronic disease conditions, and predicted expenditures for individuals 18 to 34 years old omitted due to small sample size (source: Ingenix, 2002).

TABLE 12. *Estimated annual expenditures for privately insured female employees with and without PBS medical claim in 2002*

	\$ Annual Expenditures/Pt Without PBS (192,045 pts)			\$ Annual Expenditures/Pt With PBS (207 pts)		
	Medical	Prescription Drugs	Totals	Medical	Prescription Drugs	Totals
All	3,314	1,336	4,650	6,931	2,115	9,046
Age:						
18-34	2,738	755	3,493	6,390	1,809	8,199
35-44	3,198	1,171	4,369	6,959	1,991	8,950
45-54	3,503	1,523	5,026	5,182	2,188	7,370
55-64	3,463	1,518	4,981	8,904	2,269	11,173
Region:						
Midwest	3,325	1,236	4,561	6,954	1,981	8,935
Northeast	3,057	1,411	4,468	6,392	2,239	8,631
South	3,565	1,369	4,934	7,454	1,913	9,367
West	3,065	1,208	4,273	6,409	2,144	8,553

ICD-9 code 788.41 (urinary frequency) with ICD-9 code 625.8 or 625.9, primary beneficiaries 18 to 64 years old with employer provided insurance who were continuously enrolled in 2002, and estimated annual expenditures derived from multivariate models controlled for age, gender, work status (active/retired), median household income based on zip code, urban/rural residence, medical and drug plan characteristics (managed care, deductible and co-insurance/co-payments) and binary indicators for 28 chronic disease conditions (source: Ingenix, 2002).

**CONCLUSIONS**

The economic impact of IC/PBS has been incompletely studied. The data presented indicate that a diagnosis of IC/PBS

is associated with a 2-fold increase in direct medical costs compared with costs for individuals without the disorder. To our knowledge there are no available data about indirect costs, which are likely to be substantial.

TABLE 13. *IC expenditures by service site*

	\$ Expenditures (%)
1994:	
Hospital outpt	— (0.0)
Physician office	20,954,831 (40.7)
Ambulatory surgery	23,305,305 (45.3)
Emergency room	— (0.0)
Inpt	7,221,197 (14.0)
Total	51,481,333
1996:	
Hospital outpt	— (0.0)
Physician office	22,820,538 (40.7)
Ambulatory surgery	25,380,286 (45.3)
Emergency room	— (0.0)
Inpt	7,864,134 (14.0)
Total	56,064,958
1998:	
Hospital outpt	— (0.0)
Physician office	23,184,294 (39.3)
Ambulatory surgery	27,387,360 (46.5)
Emergency room	— (0.0)
Inpt	8,351,413 (14.2)
Total	58,923,067
2000:	
Hospital outpt	— (0.0)
Physician office	36,804,504 (55.8)
Ambulatory surgery	20,122,316 (30.5)
Emergency room	— (0.0)
Inpt	9,001,117 (13.7)
Total	65,927,937

ICD-9 code 595.1 (source: National Ambulatory and Medical Care Survey, National Hospital and Ambulatory Medical Care Survey, Healthcare Cost and Utilization Project, and Medical Expenditure Panel Survey, 1994, 1996, 1998 and 2000).

**Abbreviations and Acronyms**

- CPT = Common Procedural Terminology
- IC = interstitial cystitis
- ICD-9 = International Classification of Diseases, 9th revision
- MSA = metropolitan statistical area
- PBS = painful bladder syndrome

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