

Introduction

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The burden of urologic diseases on the American public is immense in both human and financial terms and until now has remained largely unquantified. Urologic diseases encompass a wide scope of illnesses of the genitourinary tract, including conditions that are congenital and acquired, malignant and benign, male and female, medical and surgical. They can occur at any point in the course of human development, from hydronephrosis *in utero* to urinary incontinence in the elderly. They may be acute and self-limited or chronic and debilitating, may primarily affect quality or quantity of life, and may be financially insignificant or catastrophic. Some urologic diseases present with complex signs and symptoms and require extensive evaluation, while others present with classical symptoms and are easily diagnosed. Still others occur without any symptoms at all and are discovered incidentally or during screening.

The economic impact of urologic diseases is often substantial for patients and families, employers, payors, and society at large. Physician practice and patient care-seeking behavior in urology have changed dramatically in response to a variety of financial and non-financial incentives in recent years. In order to develop thoughtful public policy responses to these changes, we must have a thorough understanding of the healthcare resource utilization and clinical epidemiology that are relevant to urologic diseases in America.

Accurate information on the epidemiology and impact of urologic diseases is critical to the equitable allocation of scarce resources at the national, state,

and local levels. Indeed, as the American population ages, there is a growing need for information about the urologic health problems facing older adults. In conjunction with findings from clinical studies and basic research on biological mechanisms, an epidemiologic approach offers insights into the prevalence, etiology, and impact of urologic conditions. Translational findings from clinical and basic science research must be considered in the context of epidemiologic observations in urology.

Until this project, no authoritative omnibus had compiled a comprehensive set of data analyses that synthesized information available from myriad national and regional sources across the public and private sectors in the United States. Despite the need, reliable and valid health services data about urologic diseases have been scattered, inconsistent, and not readily available. The capabilities of the information age highlight this deficiency. There is no national surveillance system describing prevalence and incidence across all urologic diseases. Instead, various governmental and non-governmental agencies in the United States maintain a patchwork of population-based studies, observational cohorts, national interview surveys, reviews of physician practice patterns, hospital system databases, regional cancer registries, state health department health information systems, and federal, state, and private insurance claims-based datasets that can provide useful health statistics. These sources contain a wealth of epidemiologic and health services information about healthcare costs, access, and quality, as well as

trends in the diagnosis and management of urologic diseases; however, the information sources were prodigiously untapped for this project.

The overall objective of this project, *Urologic Diseases in America*, is to quantify the burden of urologic diseases on the American public. We undertook this effort with the aid of sophisticated research methodologies and experienced analytic and administrative staff. Our team included epidemiologists, health economists, statisticians, programmers, and urologists trained in health services research. We searched all potential data sources for relevant information and health statistics in order to gather current and retrospective data on all aspects of the epidemiology, practice patterns, costs, and impact of urologic diseases in the United States. This volume is intended to convey meaningful information to users at various levels of medical sophistication, including the public, elected leaders, government officials, non-governmental organizations, media outlets, physicians, nurses, allied healthcare personnel, and academic researchers.

We began our work by conducting an exhaustive nationwide search for all possible sources of health data for urologic diseases in America. This search included data sources such as the large population surveys maintained by the federal government (e.g., National Center for Health Statistics), healthcare financing agencies (e.g., Centers for Medicare and Medicaid Services), hospital consortia, insurers, physician groups, state and county medical associations, physician specialty societies, private healthcare foundations, private sources, and the published literature. After defining a universe of potential data sources, we assessed each one on the basis of relevance, reliability, validity, quality assurance mechanisms, accessibility, cost, user-friendliness, and other factors determined to be important to researchers and the public. With guidance from the National Institute of Diabetes and Digestive and Kidney Diseases, we selected the datasets most likely to provide useful information (Appendix A). These included datasets from the Center for Medicare and Medicaid Services, population-based datasets, datasets with information about healthcare utilization and costs, and those with unique features or populations of interest that added dimension to the project.

We stratified the scope of urologic practice into discrete clinical areas for analysis. Because resources were limited, we were able to address only the most frequent urologic diagnoses. Table 1 lists the conditions selected for inclusion in this *Urologic Diseases in America* compendium.

For each condition, clinical and coding experts developed a set of codes from the National Center for Health Statistics' International Classification of Diseases, 9th revision (ICD-9), the American Medical Association's Current Procedural Terminology (CPT), and the Healthcare Common Procedure Coding System (HCPCS) to define relevant diagnoses, diagnostic procedures, and therapeutic interventions.

Table 1. Conditions analyzed in *Urologic Diseases in America*

Prostate
Prostatitis
Benign Prostatic Hyperplasia
Prostate Cancer
Bladder
Interstitial Cystitis and Painful Bladder Syndrome
Urinary Incontinence
Female Adult
Male Adult
Bladder Cancer
Lower Tract Transitional Cell Carcinoma
Upper Tract Transitional Cell Carcinoma
Kidney
Urolithiasis
Ureteropelvic Junction Obstruction
Kidney Cancer
Pediatric
Vesicoureteral Reflux
Undescended Testis
Hypospadias
Ureterocele
Posterior Urethral Valves
Urinary Incontinence in Children
Urinary Tract Infection in Children
Male Health
Male Infertility
Erectile Dysfunction and Peyronie's Disease
Urethral Stricture
Testicular Cancer
Infections
Urinary Tract Infection
Female Adult
Male Adult
Sexually Transmitted Diseases

Table 2. The burden of urologic diseases in America in 2000

	Visits to Office-Based Physicians ¹ and Hospital Outpatient Clinics ²		Visits to Emergency Rooms ²	Hospital Stays ³	Total Expenditures ¹⁻⁴
	Primary Diagnosis	Any Diagnosis			
Prostate					
Prostatitis	*	1,841,066	*	7,390	\$84,452,000
Benign Prostatic Hyperplasia	4,418,425	7,797,781	117,413	105,185	\$1,099,500,000
Prostate Cancer	3,330,196	*	*	94,620	\$1,295,800,312
Bladder					
Interstitial Cystitis/Painful Bladder Syndrome	*	4,137,000	*	*	\$65,927,937
Urinary Incontinence					
Female Adult	1,159,877 ^a	2,130,929	*	46,470	\$452,800,000
Male Adult	207,595	353,065	*	1,332	\$10,300,000
Bladder Cancer					
Lower Tract Transitional Cell Carcinoma	*	832,416	*	72,776	\$1,073,803,094
Upper Tract Transitional Cell Carcinoma	*	*	*	5,184	\$64,309,807
Kidney					
Urolithiasis	1,996,907	2,682,290	617,647	177,496	\$2,067,400,000
Ureteropelvic Junction Obstruction	*	*	*	2,215	\$11,747,477
Kidney Cancer	*	279,564	*	30,045	\$401,390,672
Pediatric					
Vesicoureteral Reflux	83,791 ^a	140,098 ^a	*	5,675	\$41,725,663
Undescended Testis	148,551	215,482	*	1,298	*
Hypospadias	*	17,364 ^b	*	849	\$16,563,330
Ureterocele	*	*	*	2,818	\$16,803,712
Posterior Urethral Valves	*	*	*	148	*
Urinary Incontinence in Children	*	*	*	*	*
Urinary Tract Infection in Children	*	*	*	*	*
Male Reproductive Health					
Male Infertility	*	158,413 ^a	*	*	\$17,046,404
Erectile Dysfunction	*	2,904,896	*	8,158	\$327,626,849
Peyronie's Disease	*	*	*	*	*
Urethral Stricture	*	364,389	*	5,035	\$191,074,350
Testicular Cancer	*	14,790	*	1,907	\$21,745,500
Infections					
Urinary Tract Infection					
Female Adult	6,860,160	8,966,738	1,311,359	245,879	\$2,474,000,000
Male Adult	1,409,963	2,049,232	424,705	121,367	\$1,027,900,000
Sexually Transmitted Diseases					
	*	*	*	*	*

*Counts too low to produce reliable estimate.

^aPhysician office visits only; counts not available for hospital outpatient clinics.

^bHospital outpatient visits only; counts not available for physician office visits.

SOURCES:¹National Ambulatory Medical Care Survey; ²National Hospital Ambulatory Medical Care Survey; ³Healthcare Cost and Utilization Project; ⁴Medical Expenditure Panel Survey.

Table 3. Annual expenditures for Medicare beneficiaries with urologic diseases

	Inpatient	Outpatient	Emergency Room	Total
Prostate				
Prostatitis	\$8,500,240	\$20,557,960	\$1,283,440	\$30,341,640
Benign Prostatic Hyperplasia	\$315,000,000	\$441,200,000	\$19,800,000	\$776,000,000
Prostate Cancer	\$264,414,460	\$660,791,840	\$2,218,220	\$927,424,520
Bladder				
Interstitial Cystitis/Painful Bladder Syndrome	\$47,859,680	\$65,050,680	\$5,832,640	\$118,743,000
Urinary Incontinence				
Female Adult	\$110,100,000	\$123,700,000	\$600,000	\$234,400,000
Male Adult	\$11,300,000	\$27,100,000	\$600,000	\$39,000,000
Bladder Cancer				
Lower Tract Transitional Cell Carcinoma	\$446,062,440	\$239,802,080	\$1,139,600	\$687,004,120
Upper Tract Transitional Cell Carcinoma	\$24,814,400	\$7,625,900	*	\$32,440,300
Kidney				
Urolithiasis	\$518,900,000	\$296,100,000	\$19,400,000	\$834,400,000
Ureteropelvic Junction Obstruction				
Kidney Cancer	\$104,869,840	\$24,348,960	*	\$129,218,800
Pediatric				
Vesicoureteral Reflux	*	*	*	*
Undescended Testis	*	*	*	*
Hypospadias	*	*	*	*
Ureterocele	\$4,658,400	\$1,849,720	*	\$6,508,120
Posterior Urethral Valves	*	*	*	*
Urinary Incontinence in Children	*	*	*	*
Urinary Tract Infection in Children	*	*	*	*
Male Reproductive Health				
Male Infertility	*	*	*	*
Erectile Dysfunction	\$36,310,280	\$39,337,720	\$604,340	\$76,252,340
Peyronies's Disease	*	*	*	*
Urethral Stricture	\$6,713,200	\$28,102,060	\$538,360	\$35,353,620
Testicular Cancer	*	*	*	*
Infections				
Urinary Tract Infection				
Female Adult	\$687,600,000	\$210,500,000	\$58,400,000	\$956,500,000
Male Adult	\$376,400,000	\$81,400,000	\$22,400,000	\$480,200,000
Sexually Transmitted Diseases	*	*	*	*

*Figure does not meet standard for reliability or precision.

SOURCE: Centers for Medicare and Medicaid Services.

These codes appear in the first table of each chapter. We applied these codes to analytic files from each dataset. Wherever possible, we stratified results into major demographic groups, usually by age group, gender, race/ethnicity, geographic region, and rural/urban status. We age-adjusted certain tables at the discretion of each chapter author (so indicated in those tables). For certain economic analyses, we constructed multivariate models. Pediatric urologic disorders were selected based on the availability of data. Urinary incontinence and urinary tract infection

are each divided into three chapters—female, male, and children. The chapters on urinary tract infection are complemented by a special chapter on sexually transmitted diseases, which was prepared by staff at the Centers for Disease Control. All analytic techniques and further information on the datasets are presented in great detail in the methods chapter.

After completing initial data analyses and constructing draft tables to present information on trends in incidence, prevalence, practice patterns, resource utilization, and costs, we convened writing

Table 4. Estimated annual cost to an individual with urologic diagnosis

Diagnosis	Individual annual cost*
Kidney Cancer	\$12,155
Bladder Cancer	\$9,585
Prostate Cancer	\$7,019
Testicular Cancer	\$6,236
Urinary Incontinence	\$4,498
Urolithiasis	\$4,472
Painful Bladder Syndrome	\$4,396
Interstitial Cystitis	\$4,251
Male Urinary Tract Infection	\$2,829
Prostatitis	\$1,759
Female Urinary Tract Infection	\$1,574
Benign Prostatic Hyperplasia	\$1,536
Erectile Dysfunction	\$1,101

*Privately-insured patients 18 to 64 years of age.

committees of academic physicians with experience in health services research and detailed clinical knowledge of the conditions. At these meetings, we also shared with them detailed literature reviews that included all pertinent population-based epidemiological and economic studies in the urologic conditions of interest. These individuals provided expert feedback and subsequent input on the execution of additional analyses and refinement of the previous ones. After completing a final set of tables and figures for each condition, we asked the writing committee members to provide insight, elaboration, and interpretation—to draw qualitative meaning from—the quantitative findings. The essays they submitted on each clinical topic were subjected to three rounds of formal peer review. The resulting chapters fill this compendium.

Although the chapter authors have worked hard to identify and summarize principal findings for the urologic conditions of interest, we encourage both casual and formal readers of the compendium to roll up their sleeves and wander leisurely through the data tables and figures. The chapters are rife with large and small results, some annotated in the text and others waiting to be discovered in the myriad rows and columns. Interested readers could explore any of these findings in more detailed, multivariate analyses. Tables 2 and 3 recapitulate a few of the most salient observations regarding outpatient visits, inpatient hospitalizations, and costs per year. Table 4

summarizes the differential per-patient cost of each urologic condition.

We faced important challenges in our analytic endeavors. Foremost among these was the limited amount of data available for conditions in pediatric urology, particularly the lack of information on the costs of pharmaceutical and medical services. Other methodological limitations are listed in the methods chapter. Furthermore, each chapter concludes with specific recommendations for improving the available datasets to support more thorough descriptions of the impact of each condition.

By any measure, the burden of urologic disease on the American public is immense and deserves further attention, in terms of clinical investigation, epidemiologic analysis, and health services research.

Accurately describing the burden of urologic disease on the American public is one of the most important efforts undertaken by the NIDDK at the dawn of the new millennium. Documenting trends in epidemiology, practice patterns, resource utilization, technology diffusion, and costs for urologic disease has broad implications for quality of healthcare, access to care, and the equitable allocation of scarce resources, both in terms of medical services and research budgets. The *Urologic Diseases in America* project represents a major step toward accomplishing those goals.

