

Background, Context, and Medical History - Tracy Alexis

Like most Americans, I had never heard of Interstitial Cystitis (IC). No one among my relatives, my colleagues, or other acquaintances had ever been afflicted by IC. But then, in late 2009, I began to have excruciating pains in my abdomen. The first physician who examined me diagnosed my condition as a urinary tract infection (UTI). However, I had experienced UTIs before, and the pain I was experiencing was vastly different from the pain of a UTI! A second physician and then a third were equally confounded. Physicians, as many Americans soon find out to their dismay, are not as smart, especially as diagnosticians, as all those TV commercials try to convince us they are.

I had been thrown off my motorcycle and slammed onto the street a few months earlier by a pickup truck that crashed into me. The pickup had been hit on the other side by an automobile that failed to stop for a red traffic light, pushing the truck into my lane and causing impact with my motorcycle, creating the crash that up-ended my life. When my symptoms developed, and as they grew worse over time, I became confident that my debilitating IC was caused by xxii the motorcycle wreck, despite that doctors do not know or understand the causes (etiology) of IC.

In order to be accepted as a disease, four criteria (developed by Rudolf Ludwig Carl Virchow in 18471) must be met. Those four criteria are: symptoms; pathology; course; and etiology.

The first criterion is that the disease must have consistent symptoms. People who have the supposed illness must display similar symptoms. In the case of IC, this would be painful urination, frequent urination, and a dysfunctional bladder but there might be other symptoms as well. Physicians know the symptomology of IC and they think they know the tissue pathology but they do not yet know the course or the etiology. Within the medical community there is considerable disagreement, especially regarding the etiology of IC. The question of etiology is crucial, and it concerns many, if not most, other diseases as well.

It may come as a surprise to the readers of this book that medical professionals do not know the etiology (cause) of many of the diseases from which we suffer: essential hypertension, fibromyalgia (which I also developed immediately after my motorcycle wreck and which has vanished miraculously with the approaches outlined in this book), endometriosis, Hashimoto's disease, lupus, Graves' disease, Crohn's disease and irritable bowel syndrome, GERD, types 1 and 2 diabetes, etc. Indeed, many of the recommendations made in this book are widely applicable to other diseases, as well, especially fibromyalgia, of which I cured myself.

Most of the time, physicians just say that they don't know what ails us, and then they fall back on family history as a means to try to discover the possible causes of our discomfort. For example, if every woman in your family has suffered from breast cancer, you probably will too. But that is conjecture, not etiology! A conclusion reached in that manner is mere coincidence or crude extrapolation. One must still answer the questions: Why did every woman in the family have this disease and, if any did not, why didn't she?

Some of medicine's answers to the etiology question are quaint but they are never amusing because they have led to practices that border on the barbaric. Consider, for examples, blood-

letting in the not-too-distant past as a treatment that was reputed to have shortened George Washington's life, or lobotomies as a treatment for schizophrenia.

My diagnosis of IC was not reached immediately; in fact, I first had to endure various medical professionals' conjectures and speculations, in addition to listening to the many physicians tell me (and treat me as if), "You've just got a common urinary tract infection." Too many of those physicians, para-professionals, nurses, and other health care specialists, when they had heard of IC, had no direct experience with it. Even less could any of them recommend a successful treatment. Indeed, it may be through learning what treatments work that medical science will learn the etiology of IC.

It must also be said that many physicians are not even remotely interested in the etiology of the diseases they treat. xxiv Their view is that knowing whatever works in alleviating pain is all they need to know. This pain relief is in fact called palliative care (care that eliminates/reduces a patient's pain) but I call its underlying theory miasmatic.

Barely a hundred years ago it was generally believed by the medical profession that diseases such as measles, whooping cough, scarlet fever, and diphtheria were caused by miasmas: invisible and odorless gases that seeped up through the ground at night and infected unsuspecting pedestrians. Many of the great-grandparents of this book's readers felt that "the night air was dangerous," as if to say that the air at night was somehow different from the air during the day. What was sold to the public as medical fact in those days is regarded as superstitious nonsense today.

Discovering an illness' etiology is extremely difficult work and often involves the study of generations (that's why doctors ask for family histories), and the results are rarely welcomed. For example, there is strong evidence that many diseases which have made their appearances known since around 1960 might be the result of the patient's mother having been exposed to persistent endocrine-disrupting chemicals if she lived near a Superfund site during her pregnancy. To demonstrate this theory conclusively, as is the case in so many medical instances, would upset the legal departments of a lot of industrial corporations. (For example, watch the film *Erin Brockovich*2 .)

It became very clear that I was on my own, then, when it came to successfully healing my IC. This book tells the story xxv of the treatments I received, my own discoveries to help heal my body, as well as which treatments and self-discoveries worked and which did not—including which treatments at the hands of medical professionals made my bladder situation even worse.

My symptoms will be described as they developed, waxed, and waned. I will recount my efforts to seek help, discuss the help that I did receive, and, finally, share what—thanks largely to my own efforts—did the most to relieve my symptoms.

I hasten to add that I do not mean to disparage all physicians. Far from it! The physicians and staff at University of New Mexico Hospital, specifically those in the uro-gynecology (uro-gyn) clinic (the clinic devoted exclusively to urologic issues that plague females) were extremely helpful and detailed in their treatment approach, and I thank them now, especially Dr. Yoku

Komesu, for all they did to help me heal my dysfunctional bladder. But others at different hospitals and medical facilities, where I was required to submit myself for treatments because my health care insurance changed over the years, were not helpful! More on that later. I hope that you, as a sufferer of IC (and fibromyalgia or other chronic inflammatory diseases), are as lucky in your search for help as I eventually was!

This book does make representations of some concepts such as chemistry, biochemistry, physiology, metabolism, and xxvi nutraceutical (a food containing health-giving additives and having medicinal benefit) as established facts, and these representations deviate from what science and/or scientists may regard as valid.

As much as 10% of the world's population suffers from Interstitial Cystitis (IC), a chronic inflammatory* bladder condition that causes frequent and often painful urination. IC is sometimes called painful bladder syndrome (PBS) or bladder pain syndrome (BPS).

The bladder is a balloon in which urine is retained before it leaves the kidneys through the ureters. Once a significant amount of urine is deposited in the bladder, the urinary sphincter muscle triggers the release of urine so it can exit the body. The bladder is the active participant in this process. At the beginning of my IC, I felt like my urine was on fire. Any urine I was able to pass created a pinching sensation in my urethra (the tube through which the urine exits and goes outside the body), and the drips and dribbles of passing urine felt like burning gasoline. Physiologically, I experienced a constant sharp, stabbing pain in my lower left pelvis that remained for several years—even a soft, gentle touch in that lower left pelvic area made me howl in agony. I later learned that the pain in the lower left pelvis area was referred pain caused by nerves that were near the actual trauma area, “referring” discomfort elsewhere in my body.

I learned that many people who have IC experience painful, debilitating symptoms endlessly while others may have periods of pain dotted by random stretches of time without any discomfort whatsoever. Physicians do not know why this variation occurs, but conjecture that it may have to do with the severity of bladder damage in each patient. Medical providers do not even know how to diagnose IC because there is no scientifically agreed-upon etiology.

Unfortunately for sufferers, when medical professionals are uncertain of the cause of an ailment or disease, they are equally as uncertain of how to treat that ailment or disease. However, one of the most common symptoms of IC is urinary pain that lasts for more than six weeks and is not caused by another bladder condition such as kidney stones or urinary tract infections.

Urinary pain that persists for any length of time brings about a special set of challenges that revolve around the need to empty one's bladder anywhere from 50 to 75, or more, Interstitial Cystitis: A Personal Journey of COMPLETE Healing! 3 times per day. Obviously, such frequent urination with its sensations of burning, stinging, and even pinching makes a decent night's sleep, travel, and productive employment nearly impossible.

Common sensations suffered by patients with IC are bladder pressure that becomes more and more uncomfortable as the bladder fills up, discomfort or pain in the urethra (the tube that transports urine from the bladder to the outside of the body), and the feeling that one needs to

void again immediately after one has just gone. This feeling to void again immediately after one has just gone should not be confused with what specialists call “double-voiding.” Double-voiding is voiding a noticeable quantity of urine immediately after having just voided a significant quantity of urine. Typically, the IC sufferer voids as much as s/he is holding in her/his bladder but sometimes not all of the urine is emptied from the bladder and one must void again immediately after the first void, thus the term “double-voiding.”

There may be another IC commonality, that of bladder ulcers. Bladder ulcers can bleed and, if they do, blood will appear in the urine. Blood in the urine creates an environment where bacteria grows and flourishes. Blood in the bladder is the underlying cause of a urinary tract infection (UTI)—a source of real misery!

Most of my physicians, nurse practitioners, and health care providers appeared genuinely concerned with my discomfort and seemed that they truly wanted to eliminate my pain. Nevertheless, I couldn't get out of my mind the remark that one of my physician-friends shared with me: “The first thing we physicians learn in medical school is: Don't let a patient leave your office unless they feel you have done something to help them.” I can't tell you how many times I left a physician's or specialist's office feeling that s/he had no idea what I was going through nor how to ensure I felt helped before my exit from their office. Countless times would be an understatement.

At one specialist's office I visited to try to discover what was wrong with my bladder, there was a large sign saying, “One detailed health history is worth a hundred tests.” Unfortunately, the urologist there didn't follow his own posted admonition; he seemed extremely uninterested in my bladder health history and poo-pooed the history I shared, at least part of which I believed caused the discomfort that brought me to his office in the first place.

It did not help anyone connect the dots to my IC dilemma that more than a year elapsed between the cause—the physical trauma I experienced from my motorcycle accident—and the effect—the development of my IC symptoms. This does not mean that serious medical issues were not developing within my body during that year, only that whatever tissue pathology was starting had not yet produced the full onset of misery that caused my bladder's death. Perhaps another woman of the same age might have felt pain months earlier, or months later. These differences from one patient to another are the enigmas of IC.