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Polio Stories

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About ten years ago, a group of us sat around a seminar table to discuss Robert Frost's poem, "The Oven Bird." The professor was in his seventies, still mentally acute and physically fit, but not the Lothario he once was. He was particularly keen on the final question of the poem: "What to make of a diminished thing"?

In many ways, this is the question being asked in two new books about polio: *Polio and Its Aftermath: The Paralysis of Culture* by Marc Shell and *Living with Polio: The Epidemic and Its Survivors* by Daniel J. Wilson. Unlike the waning capacities of the aged, polio was usually an affliction of the young. With the onset of the disease, the fact of finitude abruptly imposed itself on previously healthy children and young adults who often became paralyzed overnight. Whether permanently paralyzed or not, the diagnosis of polio marked the end of many childhoods; innocence and an open-ended future were replaced with the specters of death and disability. Questions normally reserved for the old were foisted on the young. And for those patients permanently paralyzed, there were heartbreaking struggles and lifelong consequences.

Polio and Its Aftermath: The Paralysis of Culture
by Marc Shell
Harvard ~ 2005 ~ 336 pp.
$35 (cloth)

Living with Polio: The Epidemic and Its Survivors
by Daniel J. Wilson
Chicago ~ 2005 ~ 320 pp.
$29 (cloth)

Those looking for books on the medical history of polio, especially the Salk and Sabin vaccines, will be disappointed. Instead, these books capture the lives of polio victims intent on making sense of their illness and its meaning. If our lives can sometimes appear fragmented when viewed through the prism of modernity, here are stories which manage to capture a range of human experience, stories that paradoxically find wholeness in their forever crippled, sometimes broken, but always fully human subjects.

Marc Shell's *Polio and Its Aftermath* is an ambitious and thoughtful book, an effort to find cultural and historical meaning in America's "war on polio," held together by the author's personal experience of the disease. Shell compares his project to a painting, one in which he hopes to "take in the whole world of the polio pandemics" by locating the "universal in the particular." It seeks to mine and reconsider relevant cultural data for evidence of polio's more hidden expressions. It explores American life in the aftermath of World War II and the beginnings of the Cold War, an era in which polio served as yet another threat to the prosperity, safety, and independence that Americans so deeply desired. Unlike these other wars, polio has been largely forgotten. Given the grip polio once held on America, it is an act of forgetting worth noting. Shell seems to have spent a lifetime gathering observations about polio and its effects, and at least part of his project is to unearth apparently sedimented relics of the disease.

The strength of the book lies first in the personal narratives of the afflicted, which Shell navigates with great sympathy, as well as a rich sense of their broader cultural context. For example, it was commonly believed that the outcome from polio—paralytic or non-paralytic—was largely a matter of individual will. This was in keeping with the determined self-reliance of the age. It may not have seemed unreasonable, therefore, for parents and hospital staff to insist that patients perform tasks that were essential to their daily lives, such as getting to the bathroom on their own at night. The hope of caregivers was that through effort the paralysis of their patients could be overcome. Cruel as this appears in retrospect—with the knowledge that the paralysis of polio was more a matter of damage to neurons controlling movement than of will—caregivers were doing what they thought best, even as they operated under a misconception of the disease. Nevertheless, the children who were asked to do things they could not do out of "tough love" recognized the impossibility of the injunctions to get up and walk. And, as Shell notes, they often suffered under the cruelty of their regimens. Their suffering was compounded by the cultural unease about discussing disease and disability, an uneasiness often resulting in a silence which left the ill child impossibly on his own to make sense of what was happening to him.

A particularly nice insight into the disease comes in the second section, titled "Stasis and Kinesis." Here Shell compares the life of a polio victim to the simultaneous historical development of photography toward film—a strange but revealing parallel. The child with polio, as observed already, is different from the man who gets sick later in life. The declining old man has a previous existence onto which illness is superimposed; he retains the possibility of preserving some distinction between the well and ill self. With polio, however, disease comes early and affects everything that follows. Like a photograph, life is frozen. It risks becoming static. The struggle of the polio patient is to recover movement, just as film seeks to bring movement to life from still photographs. And just like the machines that would make moving pictures possible, the tools to treat polio were still imperfect and under development. The effort to restore kinesis through mechanical braces and physical therapy, and thereby to go on with one's life, is a transformation made vivid by the metaphor. To be paralyzed with polio at a early age imposed a stasis on a young life at odds with the very essence of childhood—that is, the movement from immaturity to maturity. Most of us look at old photographs and wonder where the child went. For Shell, the polio patient remembers all too well. He carries with him the physical stigmata of stasis, even as he seeks to restore a life in movement.

While his book is full of such thoughtful insights and many engaging narratives, Shell stumbles at times in telling his own story. There are awkwardly heavy-handed moments like: "Getting out of Montreal was, for me, a delivery like Moses' exit from Egypt." Or like this: "Unable to stand on my own two legs during my convalescence, I gradually came to understand Archimedes' dictum 'Give me a place to stand and I will move the earth.'" This would be a minor criticism except that the organizing principle of the book is Shell's personal experience with polio, his quest to find the universal in the particular. If at times he falters in the telling of his own story, his uniquely personal approach to the subject also allows Shell to draw broadly and effectively on cultural sources in the effort to give form and meaning to the illness. In turn, we are privy to Shell's lifetime of observations and insights about a world—his and ours—that has been shaped by this terrible disease.

Daniel J. Wilson's *Living with Polio* conveys a fair amount of history of the polio epidemic, but its primary purpose is to tell the stories of "polios" through a broad collection of over 150 first-person narratives, which it does exceedingly well. The structure of the book is the stages of disease: from infection, to hospitalization, to rehabilitation and through various degrees of recovery. But this structure is not an attempt to construct a universal experience of polio. As Wilson says, "I have not tried to construct a typical polio experience because I don't think there was one." Instead, he is a masterful weaver of multiple stories, seamlessly assembled here as various forms of so-called "illness narratives." They are more simply and accurately "the stor(ies) of ordinary Americans in their encounter with a feared disease." These stories of illness, according to one polio writer in the book (Anne Hawkins), "show us the drastic interruption of a life of meaning and purpose by an illness." That this illness "often seems arbitrary, cruel, and senseless" is for some the occasion for writing, not least as a way of speaking, however belatedly, to the fears and uncertainties of a childhood so afflicted.

As dramatic a life-change as polio could eventually bring, it typically began with a simple febrile illness. Parents transmitted their fears to their children not in words but in action. "When Grace Auden's father sped through the Iowa countryside at 80 miles an hour, far beyond his usual sedate speed, she sensed the seriousness of her illness." Soon enough the children found themselves in the hospital, and then isolated from their families on the polio wards. A predictable course of illness and rehabilitation gave some shape to the experience. But early on, the course of the illness was unpredictable. The most severe cases required mechanical ventilation—the "iron lung," a negative pressure ventilation system for those with bulbar polio. Lying in the iron lung, patients were fully dependent on their caregivers, relying entirely for their view of the world on a mirror suspended above their face and angled toward the rest of the room. Even the iron lung could not save every patient, and when someone died, "for those in iron lungs, the death signal was the passing of a nurse down the row of tanks, turning each mirror so the patients couldn't watch while a body was wheeled out in a now silent machine."

At some point after the acute attack, patients "began to take inventory of their bodies to see what still worked and what remained paralyzed." As Charles Mee says, he lay in bed "getting used to the idea that I hadn't died and taking stock of my body parts." It becomes clear that paralytic polio was a struggle almost literally to keep one's self together in the face of unresponsive limbs, deeply ambivalent emotions, and far flung hopes. Mee "carefully kept up the outward appearance of 'a well balanced, emotionally stable all American boy.' The façade, however, was maintained by 'sheer will,' for underneath was a seething cauldron of repressed emotion in which the 'damaged' and 'wounded' boy repressed the urge 'to kill.'" He goes on to say, "The common dream—and it was my dream too—was that one day we would just get up and walk again, like a real miracle, like making a pilgrimage to Lourdes and being cured by holy waters there."

Hugh Gallagher, another patient, was in his first year at Haverford when he checked himself in to the infirmary over parent's weekend with a fever. Overnight he had difficulty walking. The following morning, his legs were paralyzed. In retrospect he realized that "those were the last steps I will ever take in this world. There should have been more ceremony attached to them." And then, "I would never again be beautiful, innocent, secure in health, strong in body, confident in mind… and I would forever be crippled." Such reflections could hardly bring comfort, and for some the act of writing was the occasion to record the "absence and rage" provoked by the losses of polio. But after forty years, the young man who developed polio as a freshman in college finds that "disability is far more complex, more profound than mere physical impairment." Over time, he faces the very difficult question of whether "a life—with its share of joy and reward—(can) be wrested from this encompassing, ever present knowledge."

Living with Polio and *Polio and Its Aftermath* are fascinating accounts of a disease that we have mostly forgotten. They are not easy books to read, nor should they be. At times, I nearly reached for the medical texts on my shelves to better chart the course of the disease. It was tempting to think of these stories in medical terms. But a flight to physiology would be, in a way, a cowardly retreat, or at least a very partial (and unearned) understanding of the lives so afflicted. These stories ask more of the reader—and the doctor—than mere diagnosis. We are asked to sit at the bedside, to enter homes, to enter their relationships, to enter life as it is lived. And while these stories come from adults looking back on childhood, the questions asked of life—its meaning, its origins, and its finitude—are the questions that children themselves ask frequently and with urgency. They remind us that somehow it is at the limits of our lives—in childhood, in old age, and in illness—that we are given the opportunity to look more deeply into who we are.

Central to this story, and central to the whole field of medical ethics, is the question of "The Oven Bird": What to make of a diminished thing? Who is diminished, and by what? Is our mutability and decline a mere accident to be overcome, or the source of deep insights into our nature? Are all of us essentially diminished but for an excellent few, excellent only in the briefest moments of their greatest flourishing? Or are all of us, despite our inevitable shortcomings and manifest inequalities, in some crucial way equal in dignity? In this age in which intelligence seems to trump everything else, how should we regard the mentally retarded? In this age in which we revere the perfect, youthful body, how should we see the wrinkled face of the old or the paralyzed limbs of the young? And to whom should we go with such questions: Keats, or the editors of *Nature*?

Good stories are perhaps the best way to begin addressing such questions. The pathos of truth is better captured by the novelist or poet than by the philosopher or physiologist. But first we must learn to read, to develop our "moral imaginations." And by reading, perhaps we can learn to pay better attention to the storied lives all around us, many of them destined to be too easily forgotten. By uncovering a few such stories, and pointing us toward the deeper human questions that life with disease sets grotesquely before us, Marc Shell and Daniel J. Wilson have done us all a great service.

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