# **Reviews and reflections**

David A. Bennahum, MD, and Jack Coulehan, MD, Book Review Editors



Paul Kalanithi, MD, resident in Neurological Surgery, at Stanford Hospital and Clinics, February 5, 2014. Courtesy Norbert von der Groeben/Stanford Hospital and Clinics

### When Breath Becomes Air

Paul Kalanithi, MD (AΩA, Yale University School of Medicine, 2007) Forward by Abraham Verghese, MD (AΩA, James H. Quillen College of Medicine of East Tennessee State University, 1989, Faculty) Epilogue by Lucy Kalanithi, MD (AΩA, Yale University School of Medicine, 2007) Random House, New York, 2016, 228 pages

## Reviewed by David A. Bennahum, MD ( $A\Omega A$ , University of New Mexico, 1984, Faculty)

The author, Paul Kalanithi, MD, wrote an extraordinary memoir of his life prior to his death of lung cancer at the age of 35 in 2015. This is a beautiful, difficult, and at times painful, book that can bring the reader to tears, especially if that reader is a physician. A resident at Stanford Medical Center, he begins with his discovery of his imminent mortality.

I flipped through the CT scan images, the diagnosis obvious: the lungs were matted with innumerable tumors, the spine deformed, a full lobe of the liver obliterated. Cancer widely disseminated. I was a neurosurgical resident entering my final year of training. Over the last six years, I'd examined scores of such scans, on the off chance that some procedure might benefit the patient. But this scan was different: it was my own.<sup>p3</sup>

Growing up in Kingman, Arizona, a way station for those driving west on U.S. Route 40 to Nevada and California, a city that his East Indian-born parents—his father Christian and his mother Hindu—selected so that his father could practice cardiology where he would be truly needed, Kalanithi and his brothers had a very western American childhood. From my desert plateau, I could see our house, just beyond the city limits, at the base of the Cerbat Moutains, amid red-rock desert speckled with mesquite, tumbleweeds, and paddled-shaped cacti. Out here, dust devils swirled up from nothing, blurring your vision, then disappeared. Spaces stretched on, then fell away into the distance...My friends and I loved the freedom, too, and we spent our afternoons exploring, walking, scavenging for bones and rare desert creeks.... I found the wild, windy desert alien and alluring.<sup>pp21-22</sup>

An exceptional student, Kalanithi was accepted to Stanford University where he studied literature and philosophy, and some biology, unable to resolve an internal conflict over the call of medicine that challenged his love of literature. He went on for a Master's degree in English Literature writing a thesis on Walt Whitman, but even then was drawn to science.

But I couldn't quite let go of the question: Where did biology, morality, literature, and philosophy intersect? Walking home from a football game one afternoon, the autumn breeze blowing, I let my mind wander. Augustine's voice in the garden commanded, "Take up and read," but the voice I heard commanded the opposite: "Set aside the books and practice medicine." Suddenly, it all seemed obvious. Although—or perhaps because—my father, my uncle, and my elder brother were all doctors, medicine had never occurred to me as a serious possibility. But hadn't Whitman himself written that only the physician could truly understand "the Physiological-Spiritual Man"?<sup>P41</sup>

Kalanithi then consulted a premedical advisor at Stanford, organized his studies to complete the work in 18 months, and then finding that he had a year before he could enter medical school, went on to Cambridge University for a Master's degree in the History and Philosophy of Science.

...I found myself increasingly often arguing that direct experience of life-and-death questions was essential to generating substantial moral opinions about them. Words began to feel as weightless as the breath that carried them. Stepping back, I realized that I was merely confirming what I already knew: I wanted that direct experience. It was only in practicing medicine that I could pursue a serious biological philosophy. Moral speculation was puny compared to moral action. I finished my degree and headed back to the States. I was going to Yale for medical school.<sup>p43</sup> He then goes on to wonderful descriptions of the anatomy lab, his reactions to the required dissection of a cadaver, the initial shock before death, and the gradual necessary desensitization to, and objectification of, the dead that medical students experience. But, he also learned an important lesson from one professor.



Abraham Verghese, MD, member of the  $A\Omega A$ Editorial Board, wrote the foreword to *When Breath Becomes Air*.

Early on, when I made a long, quick cut through my donor's [cadaver] diaphragm in order to ease finding the splenic artery, our proctor was both livid and horrified. Not because I had destroyed an important structure or misunderstood a key concept or ruined a future dissection but because I had seemed so cavalier about it. The look on his face, his inability to vocalize his sadness, taught me more about medicine than any lecture I would ever attend.<sup>p50</sup>

Paul goes on to describe his years in medical school and how he discovers his pride in neurosurgery. He writes that, "While all doctors treat diseases, neurosurgeons work in the crucible of identity: every operation on the brain is, by necessity, a manipulation of the substance of our selves, and every conversation with a patient undergoing brain surgery cannot help but confront this fact." P<sup>71</sup>

After graduating from Yale he marries a classmate, Lucy, and they head back to California where Paul will intern at Stanford University Medical Center, and Lucy at the University of California San Francisco Medical Center; he in neurosurgery and she in internal medicine.

He describes the extraordinary workload that neurosurgery demands during the six years of training, and one year committed to research that Stanford requires. Not only is too much asked of the resident, but also too much of friendship and marriage, something that will be all too familiar to most physicians who trained in the American system.

While very sympathetic and even admiring of Kalanithi, I cannot see that the knowledge, experience, and excellence in neurosurgery, and all of medicine to which he aspired, is really any less than that of the best physicians in other disciplines. He writes, "Perhaps, unique in medicine, the ethos of neurosurgery—of excellence in all things—maintains that excellence in neurosurgery is not enough. In order to carry the field, neurosurgeons must venture forth and excel in other fields as well....The most rigorous and prestigious path is that of the neurosurgeon—neuroscientist." PP98–99

Perhaps the image of a knight "carrying the field" is harmful to the education and training of young doctors in whatever specialty they have chosen. Certainly 100-hour work weeks for six years is harmful. Indeed, in the next to last year of his training Paul and Lucy went through a crisis in their marriage, something that many physicians experience. Fortunately, they found their way back to each other, only to discover the catastrophe of his cancer.

But what I found most wonderful about this book is how Kalanithi meditates as he moves through his training. 

 Galanathi with his wife
 Lucy and their dependent Elizabeth Acadia

Paul Kalanathi with his wife, Lucy, and their daughter, Elizabeth Acadia. Courtesy Lucy Kalanithi

I had started in this career, in part, to pursue death: to grasp it, uncloak it, and see it eye-to-eye, unblinking. Neurosurgery attracted me as much for its intertwining of brain and consciousness as for its intertwining of life and death. I had thought that a life spent in the space between the two would grant me not merely a stage for compassionate action but an elevation of my own being: getting as far away from petty materialism, from self-important trivia, getting *right there*, to the heart of the matter, to truly life-and-death decisions and struggles ... and surely a kind of transcendence would be found there?<sup>p81</sup>

Sadly, in residency he discovers that physicians become inured to suffering. It cannot be otherwise if they are to survive to serve the next patient. He watches fellow residents who quit the field, and ponders how he can retain his compassion. He finds solace in the experiences of William Carlos Williams and Richard Selzer. He confesses "Amid the tragedies and failures, I feared I was losing sight of the singular importance of human relationships, not between patients and their families but between doctor and patient." <sup>p86</sup>

In the latter part of the book, Paul tells how he and Lucy discovered the cancer, their efforts to find treatment, their marvelous oncologist, Emma, and the decision to have a baby. "I knew a child would bring joy to the whole family, and I couldn't bear to picture Lucy husbandless and childless after I died, but I was adamant that the decision ultimately be hers..." P143

The book goes on to tell of treatment and recovery, and then the final relapse. The baby is born and there is a joyful

### **Book jacket**

naul Kalanithi was a neurosurgeon and writer. He grew up in Kingman, Arizona, and graduated from Stanford University with a BA and MA in English literature and a BA in human biology. He earned an MPhil in history and philosophy of science and medicine from the University of Cambridge and graduated cum laude from the Yale School of Medicine, where he was inducted into the Alpha Omega Alpha national medical honor society. He returned to Stanford to complete his residency training in neurological surgery and a postdoctoral fellowship in neuroscience, during he received the American Academy of Neurological Surgery's highest award for research He died in March 2015. He is survived by his large, loving family, including his wife, Lucy, and their daughter, Elizabeth Acadia.

photograph of Paul, Lucy and the baby, Kady. A lovely epilogue written by Lucy after Paul's death on March 9, 2015, concludes the book.

Even now, after a second reading and writing this review, I am brought to tears for this extraordinary man, whose spirit touches the reader so deeply.

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### By the Bedside of the Patient

Nortin M. Hadler, MD (A $\Omega$ A, Harvard Medical School, 1968)

The University of North Carolina Press, 2016, 224 pages

Reviewed by Norman H. Edelman, MD (A $\Omega$ A, New York University, 1961)



During a brief break in the action in a fellows' sub-specialty clinic, which I supervise, I was trying to think of a metaphor which would reflect the essence of this book when a staff member walked in to inform us that "the suits are here."

Indeed, there were about six unfamiliar people in business attire busily taking notes. They were not an

administrative or regulatory team, as we have increasingly come to expect, but a group of people from a well-known clinic seeking to franchise their expertise and reputation in the care of a common chronic illness. I think that in several ways this reflects the source of Dr. Hadler's unhappiness about the state of our medical care enterprise. He is mostly concerned about physicians' loss of control to the "suits"—administrators, corporate and government payers, regulators, consolidating and marketing entrepreneurs.

In this regard, the book is similar to others which

bemoan how physicians have lost the rather extensive and cherished autonomy that has been built since Hippocrates' time. And, like the others, loss of autonomy *per se* is not recognized as the central cause of the dysphoria. Instead, such a loss is claimed to have seriously impaired the doctor-patient relationship to the detriment of care.

A short beginning section describes Hadler's early training and career progress to become a "master clinician," an entity which he believes was central to the success of our traditional system, but is becoming extinct. Those who have trained in the same or similar institutions, and who are of a certain age, will likely enjoy the nostalgia.

The bulk of the book is devoted to angry attacks on specific examples of relatively recent changes which Hadler believes are destroying the profession, with the battle cry, "I am a loose-cannon internist." They include the success of the National Institutes of Health extramural grants program which favored research-oriented faculty and made clinical teaching a step-child; the misinterpretation of the cause of Libby Zion's death leading to drastic changes in resident work hours of unproven value; the Institute of Medicine's gross overstatement of the significance of hospital deaths due to medical errors, as in most instances the patients were fated to die anyway; the electronic health record, sold as a way to improve patient care but really designed to facilitate administration; and overly restrictive Medicare rules for attending physicians in teaching settings.

Handler also cites two examples that are less well known but important. One is the pervasive conflicts of interest inherent in the National Quality Forum, the entity which serves as a clearing house for quality measures proposed by most entities, including Medicare.

The other is the unbalanced composition of the Resource Utilization Committee, a committee of selected professional societies convened by the American Medical Association, that advises Medicare on the distribution of RVUs (relative value units) between specialties. This lack of balance favors the interventional specialties thus perpetuating the large gap in reimbursement between these and the cognitive specialties. The irony here is that this committee is not a product of the "suits" but of our own professional organizations.

The last section is devoted to two proposals for changing the financing of medical care. One is a form of prepaid health insurance with a twist allowing for a separate pool of funds for services that are not evidence-based but in demand by patients.

The other is an extension of the workers' compensation system with which Dr. Hadler has had much experience.

He proposes a Clinical Effectiveness Panel that has the responsibility of determining which services should be available under this system. The panel is to be composed of nine members, a majority of whom are physicians, whose expertise and integrity are so well recognized as to eliminate the possibility that their judgments could be influenced by political or other conflicts of interest—just like the Supreme Court.

In closing, I must note that I occasionally found Dr. Hadler's tone irritating. He relies on citing his credentials as support for a point of view a bit too often, and in his diatribe against a popular electronic health record he goes a step too far by including a personal attack on the developer.

I don't know how many readers of *The Pharos* will find this book to be worth their time, but it may enlighten non-physicians who simply cannot understand why physicians of a certain age are so angry at their profession that they advise their progeny to stay away from it.

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### Matthias Buchinger: The Greatest German Living

Ricky Jay Siglio, Los Angeles, 2016, 160 pages

### Reviewed by Gerald Weissmann, MD ( $A\Omega A$ , New York University, 1965, Alumnus)

Ricky Jay describes his stylish monograph as "Peregrinations in Search of the 'Little Man of Nuremberg." Jay's peregrinations form a fitting tribute to his hero, Matthias Buchinger (1674–1739), a "29 inch-tall phocomelic overachiever." The richly illustrated story of that quest includes graphic curiosities by and about this overachiever. It's a handsome, enchanting volume replete with portraits, broadsides, family trees, and coats of arms that portray the feats of skill at magic, musketry, skittles, and musical performance, all bearing the telltale signature of "Matthias Buchinger born without hands or feet."

Ricky Jay has the credentials to make Buchinger matter as some consider Jay today's greatest sleight-ofhand artist as well as a scholar, historian, and collector of curiosities.<sup>1</sup>



#### Magic and magnification

Jay has written about Buchinger before, as one in a gallery of other interesting historical characters.<sup>2,3</sup> In this volume, Jay addresses Buchinger's mastery of micrography—the art of writing texts almost invisible to the naked eye.

Enlarged images show how Buchinger

cunningly wove miniature texts into the crannies of calendars, portraits, and coats of arms. In Buchinger's posthumous portrait of Queen Anne (1718), limned in ink on vellum, the curls of the queen's hair are formed by micrographic letters that spell out three chapters from the *Book of Kings*.

In a stippled engraving from a 1724 self-portrait, Buchinger shows micrographic lettering used to form his florid wig. It spells out seven complete Psalms and the Lord's Prayer.

Jay tells us that viewers "respond to Buchinger's micrography as they do to the performance of magic: when they are stunned, or stumped, they seek an explanation."<sup>p18</sup>

### A body maim'd

Jay was drawn to Buchinger not only for the little man's skill at micrographics, by also by the story of a fellow conjurer who performed sleight-of-hand without hands.

From his childhood in Bavaria, where he was called a "thimble," Buchinger became progressively famous in Western Europe as a skilled performer. He was a whiz at card-play, swordplay, and dancing the hornpipe in a Scottish kilt. He entertained audiences at street fairs, manor houses, public inns, and royal seats. He appeared in venues from Leipzig to Dublin, and the Tuileries Palace in Paris to the Court of Saint James in London. A 1726 broadside described him as "The Greatest German Living." This in the reign of George I, the Hanoverian.

Equally surprising was Buchinger's private life. He wed four wives, and claimed fatherhood of 14 children.

Readers figuring out how this "body maim'd" became a paterfamilas, will also wonder how Buchinger mastered miniscule calligraphy without the aid of optical gadgets. Jay was also worried, and posed the question to several eminent artists. Their verdict was the use of lenses. Art Spiegelman, Erich Fischl, David Hockney, and Ed Ruscha surmised that Buchinger used magnifying lenses, possibly fixed to a ring-stand apparatus, not uncommon at the time.

#### Phocomelia, thalidomide and retinoids

Jay pays more than passing attention to Buchinger's bodily form. Evolution dictates that in phylogeny, fins come before limbs. In phocomelia, limb ontogeny stops cold. Jay quotes 18th century and 19th century authorities who speculated that phocomelia resulted from "maternal imprinting," then defined as "a traumatic stimulus encountered by any pregnant woman." Local officials, therefore, banned Buchinger from performing at fairgrounds, worried that women frightened by his appearance might bear children similarly malformed.

Epigenetic effects of thalidomide and retinoids on our inner fish serve as models of what may have happened to the little man from Nuremberg. Recent work on the molecular pharmacology of thalidomide has implicated a metabolite of the drug as a possible culprit, and permitted discovery of how the protein cereblon acts to blunt limb development.<sup>4</sup>

Both before and after thalidomide, another culprit has been implicated in phocomelia—at least in the lab. Following the work of Dr. Dame Honor B. Fell and her students at the Stangeways Research Laboratory in Cambridge,<sup>5,6</sup> studies of how high doses of vitamin A affect embryonic limb development have moved to the molecular level. Excess vitamin A affects "maternal imprinting." High-dose retinoids produce changes in stem cell differentiation that dictate how fins become limbs in the course of evolution.<sup>7</sup>

How would hypervitaminosis A account for limbless Buchinger? Prompted by the happily digressive tone of Jay's book, I'll make a bold suggestion. I doubt that Buchinger's mother munched on too many carrots; I'd suggest an overdose of *Gruenkohl*—green kale, cabbage, or kraut. Kale, a staple of the Bavarian diet, has the highest vitamin A content of any food available in Buchinger's time.<sup>8</sup>

Could a Bavarian mother have been imprinted by an overdose of kraut? That notion seems as improbable as four wives and 14 children fathered by a "Little Man from Nuremberg."

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### NeuroTribes: The Legacy of Autism and the Future of Neurodiversity

Steve Silberman Avery, New York, 2015, 542 pages

Reviewed by David A. Bennahum, MD ( $A\Omega A$ , University of New Mexico, 1984, Faculty)

This is a remarkable book by a journalist who has done rigorous research and writes with consummate skill to help the reader understand the enigma of the modern epidemic of autism. As the grandfather of a nine-year-old who is on the autism spectrum, I was astonished to find so much information on what Silberman concludes is not a disease but rather a common variant of what human society considers "normal."

The book begins with a discussion of the great, but most peculiar, 18th century scientist Henry Cavendish, who was the first to measure the density of the Earth. Cavendish had a loving, aristocratic father who encouraged his interest in science and left him sufficient means so he could avoid institutionalization and do his experiments in peace.

Partly owing to Cavendish's great wealth, his preference for solitude was often confused with arrogance, selfishness, or disdain. A fellow scientist once described him as "the coldest and most indifferent of mortals," while others characterized him as insensitive, blind to the emotions of others, or mean. But he was not a nasty or vindictive man; he simply had no idea how to conduct himself in public. After a conversation with Blagden about the Monday Club, Cavendish explained his behavior by saying that some men lack "certain feelings," declining to be any more specific than that. In his diary, Blagden sympathetically described his mentor as a man of "no affections" who none the less "always meant well." <sup>p26</sup>

Silberman describes a number of scientists whose personalities are similar to that of Cavendish. He follows a historical trail to show how autism was confused with other mental disorders such as schizophrenia in the 20th century.

The brilliant work of pediatrician Hans Asperger at the Heilpadagogik Station at the University of Vienna, is discussed in great detail. Asperger joined a tight-knit staff at the Station that included psychologist Anni Weiss, psychiatrist George Frankl, psychologist Josef Feldner, and Sister Viktorine Zak. In the 1930s, Asperger and his staff examined more than 200 children. "He came to believe that they were representative of a distinct syndrome that was not at all rare but had somehow escaped the notice of his predecessors."

Asperger's insight that autism was a common disorder or variant was published in a paper, *Autistic Psychopathy in Childhood* in German in 1944. However, his findings would remain little known to the psychiatric community until translated in the 1980s by the husband of the British psychiatrist Lorna Wing, who had an autistic child. Wing, like so many parents of autistic children, argued that her child's disorder was rare, and a continuum or spectrum.

In the United States in the 1930s and 1940s, a Jewish Austrian émigré pediatric psychiatrist Leo Kanner, who joined the faculty of Johns Hopkins University, reported on a small group of children he defined as autistic. Whereas Asperger thought the syndrome of autism to be quite common, Kanner thought it quite rare.

Kanner contributed to the notion that unloving, high achieving, professional parents were often responsible for the psychological disturbance of their children, an



idea that was furthered by Bruno Bettelheim at the University of Chicago. Fortunately, as a result of research on twins and families, Kanner realized in 1969 that blaming parents for autism was unsustainable.

Silberman goes into great detail on the struggles of parents to win treatment and schooling for their children. The recognition by the public

that autism is a common condition was helped by James Stuart's role in the 1950 film *Harvey*, and later by Dustin Hoffman's 1988 performance with Tom Cruise in *Rain Man*. Another stimulus to the public's understanding of autism was the observation by the late Dr. Oliver Sacks in his 1995 book, *An Anthropologist on Mars*, about a patient who seemed to be autistic.

The 2003 novel by Mark Haddon, *The Curious Incident of the Dog in the Night-Time*, dramatically presents autism through a single individual, and is now on the stage in New York.

Today, with the help of the Americans with Disabilities Act, autism is recognized as a disability that qualifies children for publicly funded education, physical and occupational therapies, and a number of other support services. However, there is little assistance available once a child turns 18 years of age.

For further reading, a January 25, 2016 article in the *New Yorker* by Steven Shapin, "Seeing the Spectrum: A new history of autism," reviews a number of new books on autism and provides a primer for what Silberman has so thoroughly researched and explored.

This is a book that opened my eyes, and would be a valuable resource in every physician's library.

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