

REVIEW ARTICLE

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The Value of the Patient Voice: A Review of *Salt in My Soul* by Mallory Smith

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Mallory Smith's posthumously published book, *Salt in My Soul: An Unfinished Life*, is an insightful and moving account of one young woman's experience living with a chronic, often invisible, illness.¹ Mallory was diagnosed with cystic fibrosis (CF) at age three and began writing in a journal when she was 15. According to those close to her, Mallory wrote consistently over the span of 10 years, until shortly before she died at age 25 from complications related to a double lung transplant. Much of what Mallory included in her journal was too difficult for her to share with family and friends while she was alive, yet she hoped that her writing would one day "offer insight for people living with, or loving someone with, chronic illness." (page x) As Mallory explained, "I want to create a piece so moving that people are in disbelief. And I want it to be like handing people a pair of glasses, giving them a way of seeing something they didn't even realize they weren't seeing." (page 291) Shortly before Mallory died, she shared the password to her 2,500-page journal with her mother, along with instructions for how to select excerpts for what would become *Salt in My Soul*.

As I read *Salt in My Soul* for the first time, I found myself highlighting passages and writing down my own reflections in response to Mallory's insights about life with a chronic illness. Just as Mallory had hoped, I found her words insightful on a personal level, but they also served as an important window into the patient perspective from a historical standpoint as well. Following Roy Porter's call in the mid-1980s to pay more attention to the "sufferers" in the history of medicine, many scholars have sought to give voice to the patient perspective.² Historians have employed different approaches to locate the patient voice and even critiqued the use of the term "patient," but as *Salt in My Soul* makes clear, a journal or diary can serve as a rich source of insight. In the case of Mallory's journal entries, one is provided with a glimpse into the day-to-day experiences and reflections of someone faced with a life-threatening illness over an extended period; the essay highlights how valuable the patient voice can be in illuminating key issues in the history of medicine. Many who knew Mallory were surprised by the content of her journal entries, especially given her outwardly positive demeanor, her reputation as the "perfect patient," and her numerous accomplishments, including graduating from Stanford University with honors from Phi Beta Kappa and publication of the 2016 book *The Gottlieb Native Garden: A California Love Story* with the National Wildlife Federation at the age of 24. (page viii)

As Mallory's mother reflected in the preface to *Salt in My Soul*, "this facade of perfection masked a darker truth ... a truth she shared only in the writing she left behind." (page viii) Even those close to Mallory were unaware of the extent to which she dealt with mental health challenges, concerns about opioid addiction, or recurring feelings of loneliness despite her extensive social network and "Live Happy" mantra. (page 166) While home on break from Stanford after a semester filled with multiple hospitalizations and health complications, Mallory wrote that "I'm living a double life right now, the life that goes on when I'm with my parents and with the doctors and doing treatment (the life of someone with a SERIOUS illness and serious complications), and the life of Mallory Smith, a student, a friend, an athlete, maybe to someone a girl of potential interest, or maybe just that tall girl out there who seems just like everyone else, who goes to class, goes out to eat, goes to parties, goes to the gym, does homework, etc." (page 59) Reflecting further, she noted how "it's so funny the things about you that people miss when they just pay attention to your actions and not your thoughts, how much that way of assessing someone conceals." (page 59) By being brutally honest in her writing, Mallory gives the reader a glimpse into the many aspects of her life that she kept quiet about while she was alive, including the obstacles she faced as a patient with a chronic disease, how she responded to challenges over the years, and how she found meaning.

More than a year after graduating from college, Mallory reflected on the "Stanford Duck Syndrome," an analogy that further elaborates the concept of living a double life. (page 170) As Mallory explained in her journal, students at Stanford could be likened to ducks swimming in water. From the surface, it appears as if they are gliding effortlessly, but one just needs to look under the water to see how furiously their feet are moving to keep them in motion. According to Mallory, mental health issues, in particular, were "taboo among the student body; since everyone else seems like they're effortlessly getting by, each person struggling with their mental health feels alone," in some cases leading to suicide. (page 170) In fact, as a sophomore at Stanford, following numerous complications and five hospitalizations in a year, Mallory was "in a really dark place" and diagnosed with depression for the first time. (page 98) Several years later, reflecting back on that period during her sophomore year, Mallory recalled that "I was thinking about mortality and disease progression and acceleration. And I felt helpless and vulnerable and broken." (page 98) The mental health challenges that people face in the setting of chronic illness are becoming increasingly recognized and responded to in the CF community; Mallory's testimony affirms the importance of attention to mental health and the patient voice.

Mallory explained that what she wrote about in her journal was "almost all bad," as she tended to keep the "good stuff" in her "head and heart," yet her writing includes much more than simply the challenges she faced. (page ix) For example, while at Stanford Hospital after an "ambulance ride across campus," Mallory explained that "I started thinking about how hospitals, to me, are so much more than a physical infrastructure; they act as a sort of ad hoc community center for those of us living in the parallel existence of chronic illness." (page 79) She explained that "chronic illness interferes with social connections, but it can also create other, more powerful opportunities for community." (page 79) Mallory felt that Stanford Hospital had played an instrumental role in shaping her identity and experience in college. Mallory also noted how much she enjoyed interacting with the woman who cleaned her hospital room, as she was incredibly friendly and compassionate and never brought bad news about her health. Histories of medicine could benefit from additional attention to the hospital experience by drawing from a diversity of patient perspectives. For example, while Mallory found a community in the hospital setting, others have felt alienated. As one man with CF described in an anonymous article titled "Living with CF while Black," he was often asked if he belonged to a gang or did drugs when he was hospitalized, yet based on his online conversations with white men with CF, "the frequent inquiries about drug use or gang membership were not the norm."³

Mallory's reflections about the difficulties she faced getting approval for a lung transplant evaluation provide insight into another aspect of health inequities in medicine. Since Mallory tested positive for the microorganism *Burkholderia cenocepacia* when she was in seventh grade, she was not eligible for a transplant at her California hospital because of the poorer prognosis for those with *B. cenocepacia*. Yet there were some exceptions to this rule, and she eventually learned that the University of Pittsburgh Medical Center (UPMC) would consider her as a transplant candidate. Since UPMC was out of network

for her, what followed was an extended period of “intentional stall tactics” by her insurance provider to avoid covering the evaluation. (page 222) After a distressing set of events that left Mallory without coverage just days before the evaluation, Mallory’s mother threatened to go on the *Today* show to expose the insurance company if they did not rectify the situation. It was “during this nightmare” that Mallory and her family realized that a close friend knew someone on the board of the insurance company, and their friend agreed to reach out to their contact. (page 225) While Mallory ultimately got approval for the evaluation, likely based on those efforts, the experience prompted Mallory to reflect on the fact that she had “an advantage that many patients aren’t lucky enough to possess: two dedicated, tenacious, educated parents with the resources to fight the system.” (page 224) In contrast, “the patients who don’t have that are the patients who die ... it’s so absurd it makes me shake with rage.” (page 224) While Mallory was cognizant of her advantages, this issue does highlight the necessity of examining a diversity of patient voices when using them as a scholarly source, as one voice is unlikely to represent all patients’ experiences.

In addition to highlighting financial factors that can limit access to therapeutic interventions, Mallory’s journal also provides insight into the long-lasting impact of being removed from a drug trial. In 2010, the summer after Mallory finished high school, she began a clinical trial at Stanford for the drug, ataluren. Mallory was convinced that ataluren had dramatically improved her health over that next year, yet her physicians ultimately removed her from the trial due to concerns about dangerous side effects, including hemoptysis. Devastated by the decision, Mallory wrote a letter to the research team, explaining that “when I started taking ataluren, I thought the best I could hope for would be to stay stable ... but within just a few months, I was gaining weight and my lung function was increasing despite living a less healthy lifestyle than I ever had in the past (exercising less, skipping more treatments, sleeping less, college drinking, etc.).” (page 93) Well aware of the “placebo effect,” Mallory nevertheless argued that “I believe with 100% certainty that the drug made a huge difference in my quality of life and I want that back.” (pages 94 and 95) As journal entries spanning more than 5 years illustrate, “the ataluren question” continued to weigh heavily on Mallory, as she tried to reconcile her own desire to be on the drug (and the willingness of one physician to let her take it) and her Stanford physician’s insistence that the drug was not safe for her. (page 155) While the drug company PTC Therapeutics eventually discontinued the development of ataluren for CF after a clinical trial demonstrated a lack of efficacy, Mallory’s writing illustrates how important it is for physicians to properly acknowledge and address the perspective of patients regarding the potential health benefits of experimental treatments and possible harm from trials’ terminations.⁴

Throughout Mallory’s journal entries, she provides important insight into a wide range of additional topics relevant to the history of medicine from a patient perspective, including the transplant experience. Shortly after moving with her mother from California to Pittsburg to be close to the transplant team, Mallory got a call that donor lungs might be available for her. While on the transplant floor awaiting surgery, she grappled with the “twisted reality” that someone else needed to die in order for her to survive. (page 253) As she waited in the hospital, Mallory had been aware that the surgery could be canceled at any point from the time the donor died to right before her own lungs were removed, yet she did not realize until after her own surgery was canceled that the donor lungs might go to someone else. As she explained, “what I found out later is that the entire time, those many hours of waiting, I was actually the backup candidate, which would have been helpful to know at the beginning (for the purpose of managing expectations).” (page 255) After two more false alarms for donor lungs, Mallory finally underwent a lung transplant on September 11, 2017. Reflecting on the transplant in her journal, Mallory explained that “the recovery from this surgery has been more harrowing and more painful than anything I’ve ever experienced before, and it’s a good thing I don’t remember the worst of it.” (pages 279–280) In the last of Mallory’s journal entries which began with the header “Need to remember to write about these things:”, she recalled “fear, anxiety, panic attacks, worst pain of my life, wishing I were not alive for parts of it,” yet she also expressed “hope for 2018—travel, lots of time with friends and family, being healthy and hospital free, and writing my book!” (pages 280, 281 & 282)

Despite the hope for the future that Mallory expressed in that last journal entry, the very next day, about six and a half weeks post-transplant, she developed a fever and was admitted to the hospital. As

Mallory's mother explained, the fever was a "cause for great concern" and they soon learned that she had pneumonia. (page 282) The final pages of *Salt in My Soul* include entries from Mallory's family and boyfriend as they worked tirelessly with physicians and scientists to provide her with an experimental therapy to treat the antibiotic-resistant *B. cenocepacia* that had spread to her new lungs. Mallory's father had learned about phage therapy, in which a type of virus called a *bacteriophage* is used to infect and kill bacteria, by reading about scientist Steffanie Strathdee's success in helping save her husband's life using this approach. After being contacted by Mallory's father, Dr. Strathdee enlisted the assistance of a community of phage researchers, and worked with Mallory's family, boyfriend, and others to develop a plan for preparing and administering the phage therapy as there was no established protocol in place at that time. Although the phage therapy did not work in time to save Mallory, her father explained in the powerful documentary film *Salt in My Soul* that "the autopsy did confirm that the phages had already started killing the *Burkholderia cepacia* germs," suggesting that the method might work for others.⁵ In fact, reflecting on Mallory's case in the postscript to *Salt in My Soul*, Dr. Strathdee explained that "the heroic effort to save Mallory's life sparked an international movement to propel phage therapy forward as a legitimate treatment for superbugs," and there is now a bacteriophage named after Mallory, called *BCMallory1*.⁶

Given Mallory's thoughtful and beautifully written journal entries, *Salt in My Soul* should be widely read by people living with chronic illness and the family, friends, and medical professionals who care for them. In addition, coupled with a diverse set of patient perspectives, *Salt in My Soul* would work well in courses on the history of medicine, health humanities, social medicine, or bioethics, as it provides powerful insight into so many key themes important to these academic areas, including transplantation ethics, family dynamics in the setting of unpalatable therapeutics, the role of the environment in health outcomes, the "fight for control" over disease progression, and the adjustment of career plans in response to chronic illness. (page 156) Indeed, *Salt in My Soul* inspired me to teach a course entitled, "A History of Medicine Through Patient Voices."

Notes

1. Smith M, *Salt in My Soul: An Unfinished Life* (New York: Spiegel & Grau, 2019).
2. Porter R. The patient's view: doing medical history from below. *Theory and Society* 1985;14:175–98.
3. Anonymous. Living with CF while Black. *CF Roundtable: A Newsletter for Adults Who Have Cystic Fibrosis*. 2020(Summer):22–23., page 22.
4. Cystic Fibrosis Foundation, 2017, <https://www.cff.org/node/1326>.
5. Will Battersby, "Salt in My Soul," (Giant Pictures, 2022).
6. Smith, *Salt in My Soul: An Unfinished Life*, page 299.; Eric Boodman, "A Fitting Memorial: Superbug Treatment Named for the Patient Who Inspired Its Discovery," *STAT*, January 23 2020.