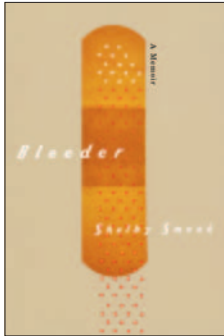


Book

Tainted blood



Bleeder: A Memoir

Shelby Smoak. Michigan State University Press, 2013.

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For more about the **tragic history of haemophilia and HIV** see *J Thromb Haemost* 2006; **4**: 2295–301. DOI:10.1111/j.1538-7836.2006.02213.x

For more about **life expectancy of individuals with haemophilia** see <http://dx.doi.org/10.1053/j.semin-hematol.2006.02.001>

For more about **Ricky Ray** see http://articles.latimes.com/1992-12-14/news/mn-1547_1_ricky-ray

For more about **Ryan White** see <http://hab.hrsa.gov/about/hab/ryanwhite.html>

Haemophilia and HIV have a history—a tragic one. During the first four decades of the 20th century in the USA, haemophiliacs had a life expectancy of about 27 years and a poor quality of life. Both life expectancy and quality improved over the next four decades. The median life expectancy at age 12 months for a boy with severe haemophilia increased to 39.7 years in 1941–60 when blood transfusion was standard care, to 53.8 years in 1961–70 with clotting factor treatments, and to 60.5 years in 1971–80 with the availability of freeze-dried concentrates that enabled treatment at home.

Unfortunately, clotting factor was obtained from blood pooled from many thousands of donors who, at the time, were not adequately screened for infectious agents. In the 1980s, the life expectancy of a boy with severe haemophilia fell to 39.8 years because of HIV. Heat treatment of clotting factor began in 1985 to stop transmission of HIV, but by then more than 50% of the haemophiliacs had already been infected. And one of these individuals was a 13-year-old Shelby Smoak.

Bleeder: A Memoir is a personal account of how haemophilia and HIV affected Smoak's everyday life. It is the story of his quest to establish his independence and to find love—tricky enough without being encumbered by illness. In 1974, aged 2 years, Smoak was diagnosed with haemophilia when a very large bruise on his back would not heal. Smoak told *TLID* that haemophilia prevented him from having a normal childhood and the seemingly endless days and weeks of bedrest and recovery further isolated him from the other children.

A few days after his 18th birthday, during his 6-monthly check-up, he was told that he had tested positive for HIV 5 years previously (he chose not to know the results when his parents offered to tell him at the time). Fortunately, he did not succumb to HIV/AIDS during the time from diagnosis to disclosure. With knowledge of his HIV-positive status came the fear of being stigmatised and ostracised—manifested by Smoak's reluctance to tell people he had HIV/AIDS. For example, he would defer telling a girl he was interested in, worrying that knowledge of his illness would end the relationship before she got to know him. Often, and poignantly, he was just delaying the agony of rejection.

Although, Smoak was not ashamed of having haemophilia, he tried to conceal the paraphernalia for his self-treatment with clotting factor when he started university for fear that people would infer that he was infected with HIV. Smoak's description of HIV as "the plague of the 1980s and 1990s" in *Bleeder* is a reminder of how much fear HIV evoked during that period, when it was indeed synonymous with

death. "At the time", he explained to *TLID*, "the media seized upon the haemophiliac stories like Ricky Ray, who was ostracised from the community and had his family's home burned down, and Ryan White, who was banned from public school, so that outside of these cases, very little existed in greater media to educate me about haemophilia and HIV." Despite the efforts of medical education and support groups to counter the stigma, Smoak and other individuals with haemophilia felt it best to live in silence until people became more informed about HIV/AIDS. He intuited that a change in the view of the virus as a death sentence would lessen the associated stigma.

At times, Smoak's descriptions of his emotional and physical pain in *Bleeder* are eye-watering. "The emotional and psychological trauma of HIV was made less painful simply by having people to talk to and by having people who cared deeply about my health and wellbeing", he told *TLID*. "If I was ever mistreated, and I was, it wasn't by anybody close to me, nor by anybody well educated about HIV."

Smoak believes that the publication of *Bleeder* has forced him to become comfortable with the topic of HIV/AIDS: "I've had to get fully behind HIV as an identity marker for myself. Sometimes, I've found this emotionally taxing, but I think moving my dialogue beyond the safety of my inner social circle was perhaps the last barrier in talking about myself and HIV and in creating a comfort that speaks to being more 'normal'."

Bleeder is Smoak's story up to 1998. Since then he has obtained an MA in English and creative writing and a PhD in American literature and theory. He also got married and now teaches college students.

Although Smoak says that he does not always understand the medical jargon, he reads about the ongoing research and developments that might help individuals who, like himself, have haemophilia and HIV/AIDS. He is also part of a men's haemophilia group in Washington, DC; the members meet once a month to talk about their lives, discuss the latest study reports, and consider their futures.

Bleeder is a bittersweet autobiography and a story that is not often told. It is upsetting at times because of the emotional and physical trauma and stigma that Smoak endures. His story is a reminder of all the other people who have been infected with HIV, including many of those with haemophilia, and what they have been through. Despite all that he has had to contend with, Smoak continuously perseveres in trying to make the most out of his life with haemophilia and HIV/AIDS. And that is an inspiring story.

Farhat Yaqub