

Dying of shame

By Cary Boyd, Ph.D.

I want to share a lesson that I learned during my childhood. A lesson I learned the hard way. The incident happened when I was in the third grade and coincided with a recurrence of my mother's breast cancer. Looking back on that final year with her, I realize that she was trying to condense a lifetime of lessons into 365 days.

The day I recall so well began like any other. My mother was visiting with several of her friends when they noticed a small, sesame-seed-sized dot moving across her hairless head. Upon closer inspection, they realized it was a louse. I watched as each friend unconsciously took a step back. If my mother noticed her friends pulling away, or if she felt any embarrassment, she did not show it. Rather, she broke the silence with laughter. It was ironic to her that she should contract lice only after losing her hair to chemotherapy. As she laughed about the triviality of lice, I felt an opposite emotion: fear. "Lice" were what the kids at school had who were called to the nurse's office, only to return the next day with awkwardly short haircuts. I was terrified of becoming one of them.

Secret: As my mother and her friends picked through my hair, guilt weighed heavily on my small eight-year-old shoulders. I knew my secret would be revealed: my mother had contracted the lice from me. I had noticed the brown sesame seeds crawling across my own head a week earlier but had kept them secret because I preferred to suffer on my own rather than face public humiliation.

Later, that evening, as my mother washed my hair with awful-smelling shampoo, she informed me that I would have to tell my teacher about the lice. I pleaded with her to let me keep them a secret. The shampoo would cure us, why should I embarrass myself further by sharing the information with my school? My mother posed this question: "Cary, is your own pride worth putting your classmates at risk?" My initial response was "Yes, of course." But somehow I knew that was not the correct answer.

Dilemma: And there, in that moment, I was confronted with a moral dilemma: to tell or not to tell.

The next day at school, I waited until the end of the day to approach my teacher's desk. I quickly slipped her a note with the dreaded truth and rushed away. Inevitably, the next morning, everyone lined up in the nurse's office for inspection; I kept waiting for my classmates to discover that I was responsible for this ordeal. But no one said a word to me. While standing there in the inspection line, I realized



SIZANNE DEJOHN

The lesson that I learned from lice can also be applied globally, to diseases such as AIDS, SARS, and avian flu.

that internalized shame is often much worse than the consequences of being honest.

To this day, I remember that lesson. Although it remains an embarrassing story, I wanted to share it now to emphasize how shame often prevents us from being honest and doing what is right.

This was clearly illustrated in May of 2007 when a 31-year-old lawyer decided to board a plane even though he knew he was infected with rare but dangerous extensively drug-

resistant tuberculosis (XDR TB). Although the transmission rate for this form of TB is low, he still put dozens of lives at risk because he was fearful of the consequences of honesty. If any of the passengers had contracted XDR TB, the odds are that they would have only a 30% chance of being cured, at a cost of up to \$350,000 per patient. I use this example not to place judgment on that man, but rather to emphasize the moral responsibility that doctors, scientists, and educators have to be sensitive to the burdens of shame that our patients and our peers are dealing with.

This lesson can also be applied globally, to diseases such as AIDS, SARS, and avian flu. The shame associated with these diseases puts us all at risk. The World Health Organization reports that in South Africa alone, one out of five people has HIV/AIDS. But because of the stigma that is associated with HIV infection, families usually attribute AIDS deaths to another disease. When Nelson Mandela's own son died of AIDS, it inspired Mandela to call for more publicity for HIV/AIDS research and education.

Stigma: It's not only infectious diseases that carry a burden of shame. Many people must endure the stigma that is associated with mental disorders. The National Institute of Mental Health reports that 58 million Americans suffer from a diagnosable mental disorder in any given year. This figure translates to about one in four adults. Yet the stigma still attached to mental illness frequently discourages people from seeking treatment.

No treatment can be entirely effective until we alleviate the shame too often associated with illness. We need to establish a precedent of honesty among individuals and among nations. Anyone in medicine or science will be confronted with the challenges of these diseases—in the clinic, the classroom, or the laboratory. And many lay people will confront such diseases as patients. I believe we have an obligation to break the silence associated with these diseases and strive to be honest physicians, scientists, and educators, as well as responsible citizens and patients.

As I look back on that eight-year-old who thought she would die from the shame of lice, I realize that there are millions of people who actually *are* dying of shame. I challenge everyone to break through the silence. There is no reason for anyone to die from shame. ■

The Student Notebook essay offers insight into the activities or opinions of students and trainees. Boyd just received her Ph.D. in physiology from DMS and is now in the M.D. program at the University of Pittsburgh. This essay is adapted from a speech she gave at DMS Class Day in June. A month after graduation, she tested positive for latent TB and so, she observed, "was again challenged to recall my own words about not being ashamed."