How illness teaches empathy

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If we can share our story with someone who responds with empathy and understanding, shame can’t survive.

Brene Brown

Recently at a social event an acquaintance I was speaking with asked, “Isn’t it hard being a doctor? People just continually bringing you their problems?”

Every once in a while, purely by chance, I read something so wonderful that I feel the need to share it. Such is an essay in a recent issue of Harper’s by the San Francisco–based American writer Rebecca Solnit. The essay is entitled “The Separating Sickness. How Leprosy Teaches Empathy.”1 Ms Solnit lures us in with an opening story of Eddie Bacon, a forklift operator from Alaska whose mysterious rashes, weakness, and weight loss confounded local doctors, but eventually led to a diagnosis of leprosy and a visit to the United States’ largest leprosy clinic in Baton Rouge, La, for treatment.1

The opening story surprises us with its juxtaposition of a case of leprosy in Alaska, as the disease is often thought of as afflicting those in more tropical climates, and the nation’s pre-eminent treatment centre housed in just such a warmer climate. In fact, in 2008 the number of new cases worldwide was 249 007—Brazil, India, and Indonesia accounted for 77% of cases reported to the World Health Organization.2 In total, 109 cases in the United States were reported to the Centers for Disease Control and Prevention in 2007.2

But the story is more complex and interesting than that. Solnit tells us the often fascinating, sad, but also uplifting story of the Louisiana Leper Home, which was founded in Carville, La, in 1894 and moved to nearby Baton Rouge in 1999, where it is now known as the National Hansen’s Disease Clinical Center (today leprosy is known as Hansen’s disease, named after the Norwegian physician Gerhard Hansen who discovered its cause, Mycobacterium leprae, in the 1870s).3 Her essay begins as a history of a disease and an institution and ends with a meditation on the nature of empathy. Along the way we learn that,

Leprosy is really two diseases: the physical effects and the social response to them. In Hawaii, where leprosy was endemic in the nineteenth and twentieth centuries, it was called “the separating sickness.” Once diagnosed, Hawaiian sufferers were hunted down like outlaws and offered a choice of exile or death. Those who chose exile were sent to a bleak camp built below the great cliff at Molokai (the leper colony there didn’t close until 1969). And Hawaii wasn’t alone. For centuries, from India to Iceland, people with leprosy—most don’t like being called lepers—were ostracized. Only in the past sixty years have even a minority of leprosy patients received truly humane care.1

The movement from ostracism to humane care began, as Solnit argues, when doctors realized that leprosy was “very nearly the least contagious disease on earth.”1 By far most of us are immune to the disease and the rest of us have a very hard time catching it. The gradual discovery of effective drug therapies has made leprosy curable, and early diagnosis and treatment prevents the disfigurement and peripheral nerve damage of the past. But,

The problems of leprosy now lie elsewhere—in the lasting stigma against sufferers, in the lack of resources for treatment in the developing world, and in the very rarity of the illness in the developed world, where doctors may not diagnose it in time to prevent permanent harm.1

In many ways the social and medical history of leprosy reminds me of so many other illnesses, both common and less common, which physicians and other health care providers see in their offices, clinics, and hospital wards every day. Because I was a medical student and resident in the 1980s and early 1990s, the attitudes of the public toward those infected with HIV come to mind. As a family physician practising today, I see that some of the same problems apply to helping those who suffer from mental illnesses such as depression and bipolar disorder. In spite of public relations campaigns featuring prominent Canadians whose lives have been substantially affected by mental illness, there is still a stigma that prevents people from seeking help and accepting treatment. Each case to me reflects a public failure of empathy—“an act of imagination, of extending yourself beyond yourself, of feeling what you do not innately feel by invoking it.”1

This brings me back to the question posed by my acquaintance. In concluding her essay, Rebecca Solnit interviews Captain John Figarola of the US Public Health Service, who is the head of rehabilitation at the Baton Rouge clinic. Figarola told her that he loved his job because he and his staff “are allowed to give care without measure—they can act on empathy.”

References