## Unclean

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 $\ensuremath{\textcircled{}^{\circ}}$  2018 Robert R. Schenck

My mother died with advanced colon cancer which took her away when I was 12 years old. I knew the local general practitioner had treated her symptoms over several months-time, without even taking an X-ray. I later realized that when diagnosed, her disease was already too far advanced to expect a cure.

She had taken me to see the Northern Laboratories new research facility being built in Peoria, and from her comments, I knew she was thinking of a scientist's career for me.

Perhaps subconsciously I was "trying to save my mother", when I reasoned I could become a doctor, a surgeon, and in fact, a "good" one! During my first two years in college, my roommate was from Ethiopia. His name was *Kebede Gebregeorgis*, or George for short. These events further confirmed to me what I could do...become a medical missionary in Ethiopia. And in my early career, that is what I aimed toward.

After accepting a commission in the U. S. Public Health Service, I was soon on my way to the U. S. P. H.S. Hospital in Redlake, Minnesota. I later requested a transfer for an extra six months at the United States Public Health Service Hospital in Carville, Louisiana. This

was the National Leprosarium, and there I was able to assist Dr. Daniel Riordan, a skilled orthopedic hand surgeon, when he would come from New Orleans to operate at Carville. When I would ask Dr. Riordan questions about the operations, his standard answer was, "Go read the literature!" And so I did. When my six months were up, I declined a "career appointment", and resigned from the U.S. Public Health Service so I could go to Ethiopia in 1960.

Upon arrival there the mission assigned me to a provincial hospital, the only one for a quarter of a million people.

Then a 40-year old female patient with "tuberculoid leprosy," appeared at my medical clinic. (For anonymity, I will call her "Beletech".) Beletech's hands had classic "claw hand" deformities, in which her fingers would simply "roll up" into the palms.

I had just one set of operative notes with me from one similar patient I had seen Dr. Riordan perform. But without full details, such as basic information how long to leave the cast on, I had to improvise. I left the cast on for six weeks to be sure healing was complete. Immediately after cast removal, and without any "retraining" by a therapist, I asked Beletech (through an interpreter) to "Pick up the glass of water with your right hand." *Much to her surprise, and honestly, even mine, she reached out with her right hand and was able to pick up the glass of water*! I then asked her to pick up the glass with her left, non-operated hand, and she could not! The fingers would prematurely roll-up into her palm, and slide along the water glass's surface without her being able to actually grasp it.

After both of her hands had been operated upon, with a similar good result, she was very grateful. And upon discharge, she bowed down to me in the hospital courtyard, hitting her forehead on the ground. I certainly did not feel as though I were worthy of such reverence, and in English, supplemented by my hand and arm gestures, I urged her to get up, looking around to see if anyone else had seen her gesture of gratitude. However, not long after this I suddenly had to leave Ethiopia to have my newborn baby with spina bifida operated on at Children's Hospital in Philadelphia. After I left Ethiopia, Beletetch walked 60 miles "out of the bush" to be shown by a co-worker to the first East African Leprology Congress in Addis Ababa.

Two years later, I presented the slides and photos of her case to the quadrennial International Leprology Congress, this one in Rio de Janiero, Brazil under the title "*Surgery Gives Hope in Leprosy.*" Workers with leprosy patients had come from around the world. Beletech's result was judged very good, even if I had only "A Series of One!", (Not twenty, nor even ten!) This experience personally informed me of my potential interests and talents. (I still have the original photos and I brought them with me tonight. They can be reviewed after my presentation)

But I was then never able to permanently work abroad again, because of my child's continuing health needs, for she needed to be within 8 hours of a neurosurgeon. So I took a job, on a modest salary, taking care of coal miners in a clinic in Southwestern Pennsylvania.

Then in 1966 I won first prize in a medical photography contest which CIBA drug company expanded with enough money for a "roundthe-world" trip to visit missionaries. In Ethiopia I learned that Oxfam in Oxford, England wanted to support a hand surgeon for A.L.E.R.T., a Rehabilitation Training Center for all of Africa, and I was advised to apply. When I visited the Oxfam Secretary for East Africa, in Oxford, England, I was abruptly told that "We want a Real Surgeon." When I asked if that meant they wanted an Englishman, or one with more training, the very same response was uttered, "We want a Real Surgeon." I concluded even if I were to work in "Deepest Africa!" that I would have to have full specialty training.

Upon return to the United States I received three offers of residency in New York. Ultimately, it would require five years of plastic residency and hand fellowship training to become a reconstructive hand surgeon. My hand surgery fellowship was with the country's number 1 hand surgeon, Dr. J. William Littler.

With my training completed, in 1972, at age 40 I returned to Chicago to the newly reorganized Rush Medical College, as Director of Hand Surgery with appointments in both the Departments of Plastic and Orthopedic Surgery.

Ultimately I trained 39 fellows in Hand Surgery, and wrote several scores of articles. After 36 years in academic medicine, I retired in 2008. We then began volunteering in African and Asian countries, I teaching hand surgery and my wife Marcia Whitney-Schenck teaching English to health professionals.

I will give you some additional prologue. In the early 1950's, as a medical student at the University of Illinois College of Medicine, I remember literally "seeing" my first leprosy patient from the doorway of the patient's room. Knowing nothing of the disease, I not only did not touch the patient, I did not even enter his room. I suppose I was frightened that if I did either action, I might get leprosy.

In 1958 as a uniformed member of the United States Public Health

Service at Carville, LA (the National Leprosarium), I had a quite different encounter. While a Sister of Charity nurse and I were "making rounds" on a leprosy patient, he suddenly had a cardiac arrest and stopped breathing.

My immediate, reflexive *ethical action* was to provide direct mouthto-mouth resuscitation, blowing in air to expand his lungs. No intervening "breathing bag" was available, as I blew air from my lungs into his lungs, and intermittingly manually externally compressed his heart. But my attempt to revive him failed. The Sister of Charity nurse grabbed my shoulder and pulled me away from the patient, ending my resuscitation efforts.

Later, I began to have second thoughts that I could have contracted leprosy myself. For months, and then less frequently as the years passed, I would Inspect my features in a mirror to see if I had developed any of the signs of leprosy, such as facial changes, or areas of skin depigmentation and numbness. None of these ever developed, and it has now been nearly 60 years since the incident.

Why did I escape? It is now believed that 95 percent of all people have a natural immunity to leprosy. Numerically, it appears that I was in that percentile group, rather than in the 5 percent who have no natural immunity. Basic to our current understanding, we now conclude leprosy is not easy to "catch"!

Though poorly understood, leprosy has been known and feared in humans for an untold number of millennia, with evidence of its existence in Egyptian mummies.

In the Old Testament scriptures, in Leviticus, if a person had even a red sore on their forehead they would be declared *"Lepers"* and *"Unclean"*. The person had to cover his upper lip, and he was to ring a bell, while crying out, *"Unclean"*, *"Unclean"*. He was not only to dwell alone, but to tear his clothes, or even to burn his garments. In the middle ages when a *"Leper"* was met and conversed with, on the path, the unclean person was to keep "downwind" for fear of contagion.

In Leviticus, Chapter 14, there were specific instructions how priestly sacrificial offerings could be made, to "cleanse" the person, his clothes, and even stones of his house. But It is conceivable that a number diagnosed with leprosy could simply have had scaly skin conditions. It is impossible now to know how many were wrongly diagnosed.

Being called a *leper* has carried with it such a stigma, it is now more kindly to refer to leprosy patients as having *"Hansen's Disease"*.

This nomenclature change campaign was due in large part to the editorial efforts of one man, Stanley Stein, a journalist who was an inpatient at the Carville, LA leprosarium. Ultimately he became blind. At Carville he had founded a quarterly publication he called "*The Star*" and through it led a life-long campaign to avoid the common use of the words *"Leper" and "Leprosy,"* and to change the name of the disease to *"Hansen's Disease"*. He had a modicum of success.

*"Hansen's Disease"* is an appropriate name, because the disease's causation by a bacillus was the earliest one recognized as such in 1873

by Norwegian Dr. Gerhard Armauer Hansen. He was the first person to microscopically visualize a bacterial disease's causative agent through a microscope.

Hansen, reported it in 1874 to the Medical Society of Christiana (now Oslo) as rod-shaped bodies in the nodules of a lepromatous leprosy patient. Koch later in 1880 identified Mycobacteria Tuberculii and both leprosy and tuberculosis were assigned to the same family name of Mycobacterii.

But over the intervening years, *Mycobacterium Leprae* has resisted growth on culture media. In addition, the latter's rod shaped bacilli have a heavy "waxy coat" thought related to bacterial resistance to the human body's defense mechanisms. Mycobacteria leprae can multiply profusely, co-existing by the many thousands within nerve sheaths, but ultimately causing decreased motor and sensory nerve function in the areas supplied by those nerves.

The typical "leonine (or lion-like) facies" of lepromatous leprosy results from leprosy's infiltration into facial structures with destruction

of nasal cartilaginous support. In leprosy, body parts, such as fingers, toes, and noses may slowly be absorbed, but they DO NOT SIMPLY "DROP OFF!"

We usually associate nerve problems with pain. Most of the time, pain is not the worst enemy. Rather *it is the "numbness" or the lack of pain that is the more severe problem!* A boy in India watching Dr. Brand try to get a stubborn key to turn in a lock, grabbed it and successfully got it to work. Unknown to him, the metallic edges of the key had torn his fingers down to the tendons and bone. The boy had felt nothing!

And a woman in India roasting potatoes among hot rocks over a fire, thought nothing of picking the potatoes out of the rocks. At that time she deeply burned the flesh of her fingers and hand, but did not know she had done so, because she had no pain.

Each of us has been born with nerves whose normal elicitation of pain protects our bodies from various harms destructive to our body's

integrity and well-being. Without pain we would destroy ourselves.

Pleasure and pain are closely integrated. If I slowly lower my body into a tub of steaming water, I can find it immensely pleasurable. But if I suddenly slipped while doing so, and the water were very hot, it could be severely painful.

Under varying situations, the same nerves can give different messages. The leprosy patient does not have normal warning sensation, and can badly suffer from extremes of temperature.

After repeated insults to their tissues' integrity, patients' fingers can suffer injury, infection, and end with shortened fingers. And though remnants of finger nails can be found on "stumps" of their hands, <u>nothing</u> has simply "fallen off."

If the facial nerve branches to the eye areas are involved, simple "blinking" may be impossible, and the eyes can become dry and infected, with ultimate blindness. Britishers Drs. Paul and Margaret Brand working in Karigiri, in south India, developed specific operations to restore the paralyzed eyelids' ability to close. Only then, could the eye corneas be protected from dryness and infection, and vision kept.

How does leprosy spread from one human to another? Gradually, over the years, most researchers have come to believe that leprosy is spread between humans by exhaled "droplets" floating in the breathed air.

How many people who are alive on the earth at this time have leprosy is difficult to estimate, but easily the number could be as high as 500,000 or even a multiple of that number. Surveillance for additional cases in developing countries is often inadequate because there are not enough public health funds and personnel. On the average, one must examine 400 "contacts" per a given leprosy patient to find just one additional new case.

It follows that leprosy's eradication is difficult in developing countries such as the Democratic Republic of the Congo and India. In both of these countries leprosy is not decreasing, but actually increasing in number. But once a case is found, a triple drug regimen of Dapsone, Rifampicin, and Clofazimine, if taken for even one month, may immediately stop further spread of leprosy to other contacts of the patient. Triple treatment for the individual may take longer to finish.

It is thought that people from China may have first brought leprosy to Hawaii, and many Hawaiians seemingly had little natural immunity to leprosy. In the 19<sup>th</sup> century it was becoming nearly an epidemic. Hawaiians with leprosy were sent to the Kalawao Leprosarium colony on the island of Molokai. The leprosarium, near sea-level, was on a low, flat peninsula at the foot of a 2,000-foot cliff, that helped to isolate leprosy patients from the rest of the inhabitants of the Island of Molokai and of the other Hawaiian Islands.

Father Damien was a native of the "Low Countries", from a Flemish speaking area in Flanders. He was a member of the Congregation of the Sacred Heart. And when his actual elder brother priest, Father Pamphile, could not go to Hawaii for health reasons, Damien was overjoyed to replace him. Damien was more of a "roughcut" than "polished" gem. He fearlessly lived, ate, and interacted with patients, himself building the patients' houses, and even making their coffins. For years he described himself as one with the patients, and after getting leprosy himself, he would say at Mass, "We Lepers!" Damien **died** of lepromatous leprosy at 49 years of age.

It will be forever unknown if Damian had exercised better hygiene in handling patient ulcers and dressings, that he could have avoided becoming leprous. In any event, Pope Benedict, the XVIth, canonized Father Damien as a Saint on October 11, 2009.

*Mycobacterium leprae* for decades has resisted being grown in Culture. "Developing an effective vaccine" is a potentially promising mantra, but no effective vaccine has yet been able to be created.

*Mycobacterium leprae* has an affinity for cooler temperatures. That is why human peripheral nerves are attacked at points where the nerves are near the skin's surface, i.e. the cooler areas near the joints, such as the median and ulnar nerves at the wrist and elbow. I would share my frustration over a lack of priority for treating functional deformities of leprosy patients.

While volunteering in the Democratic Republic of the Congo, 1 led selected staff and residents in a visit to a leprosarium some 5 hours driving time away from the local mission hospital. We asked the Sisters of Charity to show us some leprosy patients so we could screen them for possible surgery to improve function of their hands. We found seven patients who could benefit from reconstructive surgery. When we left their grounds, several woman danced with joy, ululating in their typical high pitched exclamations of joy. The first three were brought to our hospital by the Sister in charge. We reexamined them and scheduled them for surgery in that coming week.

However, that very night an indigenous Congolese leprosy worker, operating under the direction of a British leprosy mission representative in the Congo capital, took the patients out of the hospital and returned them to their leprosarium. The stated reason: there was, at that point, no therapy unit in the entire Democratic Republic of the Congo to manage their hand exercises post-surgery. Thus, no surgery could be done on them, and the authority of the Minister of Health was quoted.

While it is acknowledged that therapy is important, it could have been provided, under my supervision, by the Sisters of Charity Staff. On the telephone, I directly asked the leprosy mission representative, himself a foreigner in the Congo from Nigeria, "Do you mean to tell me that **"NO TREATMENT"** IS BETTER THAN **"SOME TREATMENT"?** To this question, there was no reply. Dreadful! The patients' joyful ululation of hope would have been fulfilled if the treatment were allowed to occur. For surgery does provide HOPE in LEPROSY!

What can leprosy teach us about LIFE? Pain, either physical or mental, in our frustrations of trying to help victims abroad, can be valuable. Some athletes have a motto, "no gain without pain"! Among the events of my life, I have a number of times been frustrated by not being able to carry out my "calling" to treat these people, who were, in turn, indeed suffering both physically and mentally. Sometimes I was frustrated by personal familial health needs, sometimes by turns of history limiting me, as a foreigner, from living in Ethiopia, sometimes by internal staffing needs and priorities of a supporting mission, and sometimes by priorities of a sponsoring foreign aid group.

But through and beyond all these limitations or frustrations, I am grateful for the amount of time I was able to care for these often forgotten, and abandoned outcasts of Society, participating in their joys and sorrows, and have been able to help transform them for the better through my reconstructive hand surgery. Thank you for joining me on this odyssey.