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## When Hearts and Hands Are Numb

"Let your light so shine before men that they see your good works and glorify your Father who is in heaven." Matthew 5:16

Just when you think that such is the part of someone else's world, stigma rears its head.

"What is that on your arm Dr. Ba?"

I hesitate. "It is a tuberculosis skin test. Positive." I say it rather matter of fact though I already ready myself for a quick explanation.

"You mean you have TB?"

That is not what the test means, but I can feel her uncertainty rising. This is one of my devoted students. She has just taken a two hour bus ride to see me. We are climbing a mountain together. Now she wonders if she should be sitting so close to her teacher.

"It does not mean I have a TB, but it means I have been exposed and now have antibodies. I should take medicine or else I have a 6% chance of getting TB sometime in my life."

"Oh that is not much."

I am glad to hear her say this as she leans back in my direction. A positive TB test simply means that I have inhaled enough bacteria of the TB strain that my system has made antibodies to it. I may never have a problem with TB. But who knows whether or not I might have a decreased immunity for some reason in the future. Perhaps I will go on prednisone for some arthritis or the like. What if I end up on chemo some day, what will the TB do then? So I take some medicine to reduce the risk of developing true disease to near zero.

Still, I pull down my sleeve. I don't want anyone else to know. I just assume that people are not frightened to be around me. What if the Rifampin makes me look orange (from orange tinted sweat) as it often does people who take it?

Much of the world has this fear of standing out.

At the moment she asked the question, I was leaning against a rocky cliff wall. We were on a ledge. We had just begun a climb to a village four hours up into the heights.

We were on our way up to an isolated village to see an even more isolated woman. At the top of the village lies the last house. Beyond that house there is a small enclosure, a yard of sorts, fenced off. Inside the closed gate is a shack that looks something like a large, boarded up dog house. Inside that shack lives a woman who looks like any 40-year-old countryside woman except for the slightest flattening of her hands.



She can no longer easily oppose her thumbs. The wasting caused by inflammation of the median and ulnar nerves has caused her to lose the ability to grasp properly.

The other villagers do not know what it is that has caused her hands to look a little funny, but they have heard of a contagious diseases that can affect the hands, feet, and

even the eyes. They have heard as well that there is no cure for this horrendous disease which causes the victim, the family and even the village to fall into ruin.

Could it be such a thing? They suspect it is so, but they dare not mention the name of the disease. The people cannot be sure, but still there is the shack, the yard, and the fence.

Here, in the countryside, one senses the stigma of infectious disease everywhere. Whether the dreaded, unspoken disease of the woman in the shack above the village, the old man in the deep valley with a cough, the woman one village over who has had months of fevers and wasting, or the baby in the city who has a black spot on her face, there is fear.

Stigma characterizes the life when mysterious symptoms arise among those living in the villages as towns.

But it could be worse.

Months later I am down in a forgotten, out-of-the-way village. It is a "Hansen's village," like several others still scattered around the province. The disease has not spared the cold northern counties or the hot tropical ones in the south.

"I was 26 when I came here."

I didn't ask Lamu the question, but she has obviously wanted to tell me her story for some time. She invites me to have yak butter tea in her home, a shabby room once designed to be a classroom in the never used school house.

The other villagers are more obviously affected than she. In fact, Lamu would never look out of place walking along the street in the city, just very poor. "But the people know," she says.

As Lamu speaks, I can't help thinking of Mr. Zhou and his wife. Lamu goes on. "I have not been back home since my son died."

I had thought she had a daughter, but she explains that the girl I once saw with her is only a niece. "First my father, then my son and husband. I had no reason to leave here after that. I couldn't leave anyway. They wouldn't let me."

Lamu starts filling in gaps for me as she pours the yak butter tea: "My son was three when I came here. I took the medicine like they said, but after I was better, they told me I could not go back to the village. By then my son was five. I did return once without permission. I wanted to see him.

"Three years later I heard that he had drowned in a water reservoir. I have not been back since. My husband died not long after that. He drank himself to death. So there is no reason to go back. My sister lives there, but her husband died also. He got diarrhea for a year. Finally, he just died. They have no money, and her daughter cannot go to school. It would only cause them trouble if I went to see."

"But, what about your parents?" I ask, remembering that I had examined her mother at her request a few months ago. She had come into the town with her mother, expressing her fear of being seen with me because it might lead to my being ostracized by the locals.

"My father died . . . well, I'm not really sure about him. I remember when I was young. I was in school. I went to the fourth grade. The other students were angry at me because my father's eyebrows had fallen out. They all said, 'Your father has leprosy!' but my father went to the doctor, and the doctor said it was not. Still after the constant rumors, my father ran off to Tibet. Some say he actually killed himself. Others say he died along the road."

Lamu's schooling ended with the disappearance of her father during that fourth grade year. It was well over ten years later that she began having some difficulty moving her hand properly and experiencing vague numbness. She, like her father, was diagnosed with leprosy in a time when staying at home while taking the leprosy medicines was unthinkable. She became the young lady in the leprosy village. The others are much older and much more disabled by the condition. As it is now, Lamu is the go-between for the villagers and the outside world.

In a small town just an hour away by jeep but far removed in living conditions from where Lamu lives, Mr. Zhou stays on a bed in the room behind his wife's shop. She sells Tibetan handicrafts though she is not Tibetan. A great business woman because of her winsome personality, her smile will sell souvenirs more quickly than a fierce bargainer any day. She seemed kind to me from the start, as if she knew that I was not a tourist, though she had never seen me before. She had guessed well, from the descriptions of neighbors, that I was the foreign doctor.

"Your son would like that," she says to me as I look at a slingshot. "I will give you a special price for him if he really wants it."

It was several visits before I really had a conversation with her. She had been having chronic headaches from a sinus infection that was never treated and they had become a constant pressure sensation. A brief exam told me that she indeed had a sinus infection.

"I had a CT back in Dali. They said it showed fluid in the sinuses."

A few days of antibiotics and anti-inflammatory meds, and she was already better, but she seemed no less troubled.

"Could I see you a moment?" she asked the next time I visited the row of stores. "My husband has diabetes, and it is getting really bad. Could you see him? He has only been ill a year."

I was busy that day so I asked her to wait a couple of days. Diabetes for a year could not yet be causing much trouble. Knowing there is no insulin available in the area, I also know that the man does not have the insulin dependent variety.

Two days later it was the day of the big "Dance of Devils" festival at the temple. Mr. Zhou's wife was in the neighboring shop talking to the lady there. She looked up and smiled but did not presume. I asked her if she wanted me to look at her husband.

"Whenever."

I felt bad to have put it off. "Is he home today?"

"Oh yeah. He is almost always here."

I was amazed at her answer. I had never seen him before. Mr. Zhou was obviously a young man. He looked early-thirties I guessed as I first laid eyes on him. "I am 31," he said when I finally asked. He quickly told me that he was on excellent natural medicine from Burma. "When I take the medicine, I feel better and don't have to urinate so much."

Then he pulled his blanket off with his right hand. "You see here?" He held up his left hand. It had a claw like shape. "I have had weakness in my left side. I think it is my disease causing these things. My first reaction was the think that this young man had had a stroke. I decided to look for other clues.

"Do you have problems with your leg as well?"

"Yes, you see my foot?"

His foot looked fine though it hung a bit limp. He demonstrated that he could not lift the end of us foot.

"Can you straighten your leg?"

"Oh sure, I can still do that."

In fact, he could raise his leg at the knee and hip. No problem. It was only his foot. He could not flex his ankle. Likewise, his arm was fine except for his hand. He could not touch his thumb to his small finger.

"Do you have numbness in your hand or foot?"

"Both."

"Do you know, when you pick up a glass of water, if the liquid is hot or not?"

"Not at all. I cannot feel. I dare not touch anything that my wife does not hand to me." Of course he was smoking as he spoke. How long will it be before he doses and burns his two fingers severely?

Already almost sure of my diagnosis, I press on. "Can I see your neck?"

As I looked at Mr. Zhou's neck, there was no longer any doubt in my mind. His left auricular nerve could be seen without his turning his neck a certain way. I felt and the nerve was hard and swollen like a pencil under the skin.

"Seems my veins have gotten hard!" Mr. Zhou blurted out as I sat back.

"These are nerves, not veins. How about skin rashes, patches, numb or white areas?"

"No skin problems at all."

Curiously, he is even more rare than the usual person who has his disease. Only 4% of the patients with his problem have no skin lesions. The other 96% have classic skin changes that make the diagnosis more sure. Even now I hesitate even to record what I dared not say without consideration and prayer on that day.

It is leprosy.

Leprosy! It is a term that cannot be spoken without hushed voice in these places. How I desire that the name leprosy would become as benign as the words diabetes, hypertension, or hypercholesterolemia. All these diseases are more serious, more difficult to treat, and more likely to kill than leprosy. Yet, the most feared name in medicine, in these parts, is "leprosy."

Nearly impossible to transmit, and completely impossible to transmit after 48 hours of treatment, the disease provokes a fear such that a man will leave his wife and child, move to a remote hut, and live like a virtual animal, nearly forgotten, and forever feared. A woman, like Lamu, will do, and has done, the same.

Could Mr. Zhou be facing that very fate?

I wondered as much as I stole back into their store three days later, having done more research to make sure there were not other things to be considering. However, the most likely cause (in fact, the only cause, I was sure) of this man's problem had been narrowed down to one, and that one, I dare not say.

But I must.

I crept into the store that Tuesday as if spying or planning to steal something. The husband was excited about his hand. "Look, the new medicine is working!" Of course, the hand looked no better to me. He could strain and make contact with the thumb and fifth finger, but it was not easy and his strength was minimal.

I sat down, made sure the door was closed, paused momentarily, and finally looked back at the wife and then at the husband.

"There are several problems that you have here, Xiao Zhou," I began. "You have loss of pain sensation in a hand and a foot. If you had this problem in both feet or just one foot, I would think that diabetes had caused it. However, you also have loss of movement. Perhaps you have neuropathy and a stroke. However, the nerves are injured in various places. Also you have nerves that are swollen and even visible in your neck. Diabetes does not cause this, I am afraid."

They listened silently and offered no comment.

"Therefore, I believe this is caused by infection. The name of this disease must not be said aloud around here because the people do not understand it, but actually it should not be feared. You can reverse some of the effects sometimes, stop the spread in the body, and stop the spread to others by taking medicines. It is easy to treat, but the people here do not understand. Better yet, the medicine can be received for free. It will not cost you money, but it can be very costly if you do not get treatment soon."

Still, there were no comments from the couple. There was only quiet nodding and seemingly unalarmed understanding.

"I believe you have leprosy." I waited for the reaction, but there was none. "Have you heard of this disease?" He nodded reluctantly, but she shook her head.

"We have this problem a lot where we are from. Many have diabetes," the wife offered.

"But this is not from his diabetes. It is separate." I went back through the explanation again. In the meantime, I also called a friend in the part of Yunnan where the man's family is based. A foreign liaison often helps smooth such things out.

"It's OK, I have a relative in the office there," said the man, who seemed to understand the gravity of the diagnosis as well as the need to be discreet.

"Will you be back home any time soon?" I asked.

"I go back home in two days."

Perfect. If the man could possibly get the medicine in his hometown, then come back, the people near him would be safe, and he would not suffer from their fears.

"Would you stay for lunch?"

I had just told this man and his wife that they need not fear this disease. Still the notion of eating from a common bowl with a man with active leprosy gave me reason to pause.

But I staved.

We had a fun and lively conversation. The couple is very friendly and seems very warm to each other. We talked of getting back together when he and I are both back in town. I would soon leave for a nearby city for two months. After the meal, I reiterated the need to be sure and get the medicine while he was in his home town.

Two days later, I was back one last time at the monastery across the street to see a lady with stomach problems. Mr. Zhou's wife was friendly as usual. He was gone.

I left the next day. So began the wait.

Will he really get the medicine?

I wondered. In fact, my mind was loaded with questions. Does he really understand the implications? Does he believe me? Does the wife really not know more about this disease than I told her? Will she stay with him? Will he get stuck at home? Will he be rounded up? Will she get the disease in time? Will people find out and run them out of town?

Several days later, I am in the cancer ward at a big city hospital talking to patients about (what else, it seems) the prejudice they feel from people who are afraid of catching their disease. I mention the poor education of the masses concerning cancer, most diseases, and, by example, leprosy.

"Oh, leprosy!" said one of the older ladies. "In our town, if someone was ever found with leprosy, we took them up on the mountain and burned them."

I shuddered and thought of Lamu and Mr. Zhou.

"In our village we treated them well," says another. "They two victims did not have to leave town far, and we would leave potatoes by the road twice a year for them to come pick them up. Years later, they returned to their homes."

Imagine the irony! While Tibetan society so greatly fears leprosy which is rarely seen, rarely transmitted, and curable, these same people have not concern about the AIDS epidemic that is raging just south of them. In fact, there is no doubt that the virus will sweep north with great momentum due to the loose moral ways that are rampant as a rule.

Two years ago, I tried to interest the director of the county disease control department in a team of AIDS prevention workers who could be arranged to come visit the health school, teach a seminar for the local public school teachers (who wield the greatest influence among the locals), and even visit the hospitals where doctors don't seem to really understand the disease or take adequate precautions against its spread.

"We don't need that teaching here," he said without discussion. "It is in other places, but no one here could have it." With that, he indicated quite clearly that the topic was not open for debate.

Since that day, there have been some banners put up to coincide with the national anti-AIDS day, but public awareness among Tibetan counties has been next to nothing.

And yet, the poor individuals with early, treatable, relatively un-threatening leprosy are ostracized along with their *unaffected* offspring even to the second generation (thus far).

The modern thinking is to come up with some far reaching plan to educate the masses about the low risk of one disease while emphasizing the true threat of another. There are charts, diagrams, harsh words, prophecies of doom, etc. How often it is that we think of the short term in our urgency – a dissemination of slogans, an encouragement of pledges, and a raising of hands.

And yet, urgent as the need may be, the society here seems to be completely unaffected by such ploys which aim to curb disease where lifestyles must first be changed, traditions much fall, and the very hearts of individuals must yield.

Hearts change one at a time. Global disease is treated one patient at a time.

Jesus had a global plan, but He carried it out person by person. If we give up working with people one by one, we will never reach them in a public address. Even though one may have an aim at reaching the entire world with a message, the message must be lived as much as spoken.

The message of the gospel, like the treatment of disease must be lived out in the lives of individuals, and witnessed by individuals, if it is to be presented to the masses.

Here in these Tibetan villages, people will not hear what one says until it is clear that the heart of the messenger is very much engaged with the people. At

least, such has been our experience. And the joy of bonding with the faces, stories, and unsavory cuisine of these dear people encourages the heart to sing of the mercy which has stooped to each child of the Merciful One, as many as have tasted it, individually first and then corporately.

As I thought of the terror of AIDS coming to this unprepared land and the dark pit of leprosy mixed with ignorance, the notion kept coming back again and again that these dear people have a more terrible dilemma with which they must contend. And ironically, the affliction that has befallen the scattered diseased ones among them may be used to open their eyes to the doorway out of a deeper pit than AIDS, leprosy, or ignorance can dig.

How we would love to see a massive turning to the Savior sweeping through this dark land where life is amazingly cheap, death so enormously feared, and where disease so relentlessly feeds off of the ignorance.

Therefore, since the children share in flesh and blood,

He Himself likewise also partook of the same,
that through death He might render powerless
him who had the power of death, that is, the devil,
and might free those who through fear of death
were subject to slavery all their lives.

With a hopeful heart, I returned to see Mr. Zhou in late April to see what had become of his situation. Would he be improved? Would he have any side-effects to the medicine? Would the store even still be there? Had anyone learned the secret?

Hebrews 2:14, 15

The man and his wife were both there. The man was wearing dark glasses and smoking. Both were ominous signs. I asked him to step in the back of the store with me.

It was dark inside, so he took off his glasses to see.

My heart sank. His right eye could not close. There was also a drooping of the left corner of his mouth. It is characteristic of leprosy to affect facial nerves on either side of the face but at different branches.

"Oh no, it's worse!" I said to the man.

"Of course it is worse!" said the man back at me. "Diabetes is very difficult to cure!"

He seemed perturbed with my noticing his facial problems. I noticed his hand was virtually useless. He walked with a limp now.

"So you did not get the medicine?"

"The doctors said you don't know what you are talking about. It is all because of diabetes. You are no specialist! You don't know about diabetes."

How I pleaded, reasoned, argued those two days! I finally was left with no alternative but to go to the disease control center. I asked Mr. Zhou about going with me.

"I will not! You bring the man here! I don't care what you do. I will prove to him that I am fine!"

I could barely choke out my words as I left. I turned to his wife, "Please forgive me if your husband becomes ostracized from the disease control director coming. I have no choice."

"We will not blame you. You are just mistaken, mixed up, and ignorant about these things," she said coldly. It was very hard to hear her speak so when she had been so warm before.

I called the disease control man that afternoon. He was actually quite cordial saying he would be glad to come with me the following afternoon. Markus and I would pick him up. I sort of dreaded going to the man's office because his office coworkers had been so rude the one previous time I had gone.

As it turned out, he came out without us having to go in. He was in formal uniform (similar to that which C. Everett Coop wore when he was Surgeon General). Again my heart sank thinking about how everyone would understand the meaning of this man visiting Mr. Zhou. I was noticeably agonized as I explained to the director how I wanted to protect this man, but he had made it impossible.

"It's OK. We can help him." The words were so matter of fact, but I was comforted even in my doubt.

We arrived at Mr. Zhou's place, and to my amazement there were large crowds of people all around. There was some tourist festival going on because it was May 1<sup>st</sup>. I hadn't even thought about the holiday because of the tension with the man. With all the people there, no one would notice the director slip into Mr. Zhou's place.

The director ended up being a true answer to prayer. He was brilliant.

"I could tell you had leprosy the moment I saw you! Let me tell you what will happen to you if you do not take your medicine!" He went on in no uncertain terms about the horrors of untreated leprosy. Just as he go into a description of what life would be like without a nose, he threw in a point that made my heart leap.

"You know that know it is the law that we must be careful to protect your identity. It is illegal to expose the name of someone who is on the medicine."

By the end of our meeting, I was thinking that this situation could not have turned out better in my wildest dreams. The men were chatting in a friendly way. Mr. Zhou and his wife were asking me to stay for lunch and thanking me for help as if yesterday had never happened.

"I will leave tomorrow to get the medicine," Mr. Zhou said emphatically. Again, he invited us for lunch.

We took our leave. I was filled with appreciation for the director. Despite his coldness in the past, his rejection of the AIDS proposals two years before, I couldn't help thinking that his matter-of-fact statements may well have saved Mr. Zhou's life.

Then, there was the grace upon grace.

I thanked him heartily as we parted outside his office. He turned as if searching for something to say back. Then, after a long pause, he started. "I must say that you help me more than anyone around here. This is the second patient you have diagnosed. I can tell you are no ordinary doctor. You care for people. You are kind, and you want to help. Markus has done so much too."

"We are happy to work together," I answered, pleased to have such cordial words. Thinking the conversation was over, I was getting back into the jeep, but the director was not finished. He had a request.

"I should tell you that I have been given the responsibility of dealing with the AIDS problem here."

I very slowly and carefully acknowledged the statement, "Really?" "Yes, we are all quite nervous about it."

"Well . . . I know of some folks that could help some training of students, doctors, teachers, etc. Would you like me to arrange something?"

He beamed. "Would you? Great thanks! That would be great, indeed!"
Global plans yes, but one person at a time. Will the public thinking ever turn? Will the fears ever be placed where they should be? Will the darkness ever comprehend the light?

Oh, how often we get tied up in our strategies as if He needs some advice! Movements are so often the visionary dreaming of men. Focusing on numbers, sensationalism, and, dare we say it, glorification of men and methods.

Following His lead to love people one by one has opened a door to the whole community perhaps. First, He lays our strategies on the shelf. Then, He teaches us the improbability of change, even the impossibility of it. Then He shows that it shall happen.

But by His Hand. It must be clear. Some plant. Some water.

But God . . . He causes the growth, if there is to be growth. If there is to be a movement, there must be a small body at the beginning. If there is to be a small body, there must be one heart change at the start.

There is hope for Mr. Zhou, at last. Hope for Lamu indeed. Hope for the whole community, all the way up the mountain to the shack, and all the way down the valley to where the man coughs alone.

Again and again, we see that it is all Him. He allows us to stumble onto the paths He has so graciously carved for our wayward feet. May it be that it will be clear above all else that without the Hand of mercy, these paths, these opening doors, and these turning hearts would all be impossible.

"That which is born of the flesh is flesh, and that which is born of the Spirit is spirit. Do not be amazed that I said to you, 'You must be born again.' The wind blows where it wishes and you hear the sound of it, but do not know where it comes from and where it is going; so is everyone who is born of the Spirit."

Nicodemus said to Him, "How can these things be?"