THE CALLING

I was working as a doctor in a makeshift Nicaraguan clinic. My physician-husband and I were part of a volunteer medical group offering short-term care to rural residents. Under a roofed veranda that wrapped around a local school, we'd set up services roughly three hours by car from the nearest large town. A small breeze flowed between the veranda's pillars, offering faint relief from the heat.

Each of our group of five – two physicians and three nurse-practitioners – had a small table and two chairs, along with basic medical equipment, such as blood pressure cuffs and stethoscopes. We sat with our backs to the privacy screens we'd roughly constructed using long curtains suspended from rods surrounding and separating two examination tables intended only for the sickest of patients. Because our clinic only offered primary care screening and basic medications like Tylenol or treatment for high blood pressure, we lacked rudimentary equipment for pelvic examinations, let alone the ability to conduct specialized exams on women exhibiting signs of cervical cancer.

My husband and I spoke with patients, one by one. Some had come to exercise a rare opportunity to ask a doctor or nurse a question or obtain long-awaited medication. Most appeared energetic and well. They chatted eagerly with neighbors and friends while waiting in a long line snaking out of sight beyond the edge of the school.

As I was soon to find out, others had made the long trip – many on foot – because they had far more pressing concerns. They'd found a way to get there, even if that meant using

innovative forms of transport for ailing family members. Several mothers, for instance, carted children in wheelbarrows padded with blankets. I had not witnessed any strollers in this rural area, imagining the difficulties of navigating a stroller through rutted dirt roads.

As word got through the crowd that I was an obstetrician and gynecologist, my queue shifted predominantly to female patients. Many came with questions about painful periods, contraception, or how to improve their chances for pregnancy.

How I First Met Maria

We had been attending to patients for several hours when I noticed a commotion in my patient line. From near the back, a middle-aged man was pushing a wheelbarrow cart with a grown woman folded into it. She barely fit, the wheelbarrow too small to hold an adult body, her legs dangling over the side, her feet sometimes bumping the ground. The man worked steadily to move the two of them up through that long line. His brow was furrowed, and he was sweating from the effort. I watched him ask over and over if he could move the two of them up to the front. When he arrived, I could see that the woman looked dangerously pale and thin.

"Her name is Maria," the man said. "She is my wife." I got out of my chair and moved toward them, and together we wheeled Maria back to one of the examination tables. "I'm very worried about her," Maria's husband told me. "She is losing weight and has little energy to take care of our three children." When we moved Maria to the table, I noticed a dark, circular stain on the back of her skirt. She had been sitting on a rag stained the same purplish-black color. The rag and skirt stains looked and smelled like old blood.

I asked Maria about her medical history. She was forty years old, although I would have guessed fifty. She'd been having back pain and abnormal vaginal discharge for months. The last three or four months, the discharge had become bloodier and a bright red color some days, darker other days. Unlike the

flow from her period, this bloody discharge was constant. She'd had no trouble with her urine or bowel movements but was feeling exhausted all the time.

I finally asked the question I'd been dreading because I felt I knew the answer: "Maria, have you ever had an examination called a Pap smear? Or any type of examination of your vagina or opening to your womb?" She and her husband looked at me blankly.

"We had midwives for our babies," her husband said proudly. I would learn that Maria's experience was typical of many women in lower-income countries, who only get medical care when they're pregnant – if then.

"I would like to do a gentle examination of your vagina with my fingers," I told Maria. "To see if I can learn anything about your bleeding." I covered Maria's waist and legs using a sheet from the exam table. I helped her gently slide down her undergarments, had her open her legs with her knees falling apart, and, using the two gloved fingers of my right hand underneath the sheet, I slowly examined her vagina. At the top, smooth tissue gave way to a firm and irregularly bordered mass five centimeters across and extending outside her cervix and into the vaginal tissue.

My heart sank. I was sure Maria had cervical cancer.

The Stark Realities for Lower-Income Countries

In this isolated area, I lacked the means and equipment to offer Maria anything more. The nearest regional hospital could confirm the presence of cervical cancer with a biopsy, but even a reliable diagnosis provided no guarantee the hospital had the means to treat her cancer.

What should I tell Maria and her husband? How could I help? I told them I was worried something was growing at the top of Maria's vagina that should not be there and urged her to see the specialist in town. I asked her husband if he knew anyone who could give them a ride to the central hospital.

As her husband stepped out from the curtained area to ask for a ride, Maria turned to me. "Doctor, tell me, do I have cancer?"

I took a deep breath. "I cannot know for sure without doing a biopsy," I told her. "That is why I want you to get further testing and treatment. But I am very worried."

With an audible groan, she closed her eyes and turned her head away from me. I could feel her chest moving with quiet sobs as my hand rested on her shoulder. We stayed there, silent, for what seemed like several minutes. Maria took a breath, rolled her head back to look at me, and through both of our tears we held each other's gaze in mute understanding.

Then Maria breathed in again, her lips pursed, and with a grunt she tried to push herself up on her elbows. She seemed to be summoning resolve to face her prognosis. Too weak to sit up on her own, she asked for help getting dressed. I guided her back into her wheelbarrow. By then, her husband had come back, saying he'd found a ride into town for the two of them.

He pushed her back out into the crowd, and I watched the back of Maria's head rise and fall with the ruts in the road. I never saw Maria again.

Cervical Cancer Ruthless – but Preventable

It was the fall of 1991 when I met Maria, but I cannot forget her. I can close my eyes and capture the image of her rolling away in that unpainted wooden wheelbarrow, her feet bumping against the rutted road. I can retreat to my core and feel my hand on her shoulder, Maria quaking with quiet sobs as she came to grasp her diagnosis. I vividly remember the moment of profound connection when our eyes met, and without words, she told me she knew about the progression of her disease, that it would soon rob her of her future.

I wish I could say that meeting Maria was a one-time experience, but it's not. Working and traveling worldwide throughout my decades of caring for women as an obstetrician and gynecologist, I have seen too many *Marias* – women with advanced cervical cancer in a setting where treatment is either sparse, too

expensive, or unavailable altogether, as it was in rural Nicaragua in 1991.

But I have encountered other *Marias* in all settings, across oceans, above and below the equator, in clinics where women came dressed in expensive designer shoes, and in dusty village squares where patients wore plastic flip-flops. I have met *Marias* in Texas, where I received my residency training and then worked in a farm workers' clinic on the Rio Grande border. Some *Marias* I met while working in Africa – both caring for patients and as a consultant helping African health departments design their cervical cancer prevention programs. Other *Marias* I have encountered in Seattle, where I've had the privilege of providing care for over thirty years in a women's clinic at Harborview, the largest public hospital in the Pacific Northwest. Sadly, I can say that *Maria* lives in all places, all settings, and has been present with me my entire professional life.

And while the *Marias* have left an indelible mark on my spirit and heart, by contrast, I want to lose sight of their killer, cervical cancer – a demon I would dearly love for this world to exorcize. I am keenly aware that this task is too big for one person. The onward march of cervical cancer – its deft thievery of lives, the vitality it steals from its victims, their families, their communities, from all of us – shows no sign of abating. Despite any efforts to stop it, cervical cancer is relentless and ever-increasing.

And yet, this form of cancer *should* leave. This relentless cancer that strikes women in the prime of their lives, this stealth killer that is especially skilled at striking the unsuspecting individual who may have never heard of it, or did not know it could be prevented, or did not have access to the health care that could prevent it – this cancer *should* leave.

Be gone, cervical cancer. Release your death grip on women.
You are a preventable cancer, after all.

Stop for a minute. Take that in: "a preventable cancer." Just think how rare it is to have those two words, *preventable* and *cancer*, together in one phrase. What does that mean?

Well, it means that medical providers know what causes cervical cancer, how to treat it and cure it if it's found early enough, and how to prevent it. Cervical cancer is a cancer that could be eliminated, that need not exist at all. Yet, this preventable cancer kills a woman somewhere in the world every two minutes. That translates to 360 women dying a day.

Women dying. From a preventable cancer. Three hundred and forty thousand deaths a year. Six hundred thousand persons with cervixes diagnosed a year – and, if they do not die of cervical cancer, the treatment leaves permanent scars on both body and soul.

My Journey toward "Enough"

I've finally reached a place in my personal and professional life where I can no longer stand by and witness so much suffering. I need to shout out to the world from the rooftops: *Enough! Enough Marias. Enough unnecessary death and suffering.*

I can no longer tolerate hundreds of needless deaths a day, because my career has allowed me to follow the near-miraculous advancements of cervical cancer prevention. As a consultant for the World Health Organization for more than a decade and one of the recent authors of a set of global recommendations aimed at eliminating cervical cancer, I know it's possible to offer increasingly effective screening tests for this disease, both to lower-income countries and to impoverished, marginalized communities in higher-income countries. I know that these tests can pick up pre-cancerous abnormalities in persons with cervixes, and that effective treatments can resolve pre-cancer before it becomes cancer. I know that these treatments, just as with screening, can work within communities and countries of all financial and medical means. I know that if a person has developed cervical cancer and it's found early enough, the cure rate is excellent. And perhaps even more astonishing, I know we already have a terrific, lifesaving vaccine that can prevent more than 90 percent of cervical cancer. And yet, with innumerable ways to prevent these 360 deaths a day, we continue to let them happen.

Enough, I think to myself. *Surely – surely if people just heard the stories of the amazing women I've met, the patients I've cared for, they, too, would be moved*. In publishing this book, I thought I could open people's eyes once they'd heard from the brave women who stepped forward and allowed me to tell their cervical cancer stories – that sharing their suffering might prevent further suffering, further death.

I write these words and share other women's stories with humility, knowing that as I've tried to convey the voices and perspectives of many people – patients, clinic providers, community leaders, journalists, professors, and politicians – I also have my own personal perspective and beliefs to share. I write with the hope of finding like-minded others, no matter their background, country of origin, or personal circumstances.

I am a woman raised in the western United States, in a country where I had the opportunity to go to college and medical school and pursue advanced medical training. I am White, and I am talking about a disease that kills more women of color. In addition to working in medical clinics in my own country, labeled "high-income" by the World Bank, I have lived and worked as a physician in Liberia, Nicaragua, and Kenya – countries deemed "low-income." While I am a passionate advocate for those who have been attacked by this cancer, I am not a cervical cancer survivor. I've never had to fight to obtain health care. I am acutely aware that my perspective arises, in part, from a place of privilege.

I own my perspective as a physician who has provided patient care to women for decades across many countries and within communities filled with women of varying needs and financial means. Caring for women and bearing witness to their courage as they confront illness; witnessing their immense power as they birth children; being privy to their deepest concerns in moments of profound vulnerability: my role in these women's lives has been, and continues to be, my deepest privilege and my greatest inspiration. I am a fierce believer in the power of women.

I also own my perspective as a person whose cervical cancer expertise reflects my work with thousands of female patients, in conducting research on infectious diseases in women, and, by assisting the WHO to develop policies that improve access to and understanding of the human papillomavirus (HPV) vaccines (Box I.1), a critical tool in cervical cancer prevention, and cervical cancer prevention guidelines to enable countries to lower their death rates from cervical cancer. I have worked in consultation with the health ministries of several African countries, such as Namibia, Malawi, and Botswana, toward developing their own cervical cancer prevention guidelines. This work has offered me a place at the table with global leaders and researchers focused on preventing cervical cancer worldwide and has allowed me to have everyday conversations and interactions with those who oversee important cervical cancer screening in African clinics located in Namibia or in Malawi.

While I have written many academic articles and textbook chapters, presented data at international meetings, given countless lectures, and taught budding doctors and medical students how to do pelvic examinations and deliver babies, I have never

Box I.1

HPV vaccines bolster the immune system to offer protection against HPV infections. Because HPV is sexually transmitted, the vaccine offers maximum protection against the types of HPV infection that can cause cervical cancer when it is given before initial exposure to HPV – essentially when persons with cervixes are young or before they've had sex for the first time. The vaccine also creates a stronger immune response in girls under fifteen and requires fewer vaccine doses. That's why the World Health Organization recommends giving the HPV vaccine to nine- to fourteen-year-old girls.

written a book like this, geared toward a non-medical audience, about a disease that should not exist but continues to kill.

But I must do my part, knowing it will take a far-reaching, global effort to conquer this cancer. I'm willing to spread the word to anyone who will hear it. That word, the word that pushes me to keep going, is the title of this book: *Enough*.

Enough, because cervical cancer can be stopped.
Enough, because each of us can play a role in making it stop.

And, because my former patient, Maria, isn't here to say this out loud, I will speak on her behalf by saying that women are worth it. All women are worth the effort. Intrinsically, we all know that. But it will take all of us – working together – to show how passionately we believe it.

Part One
A Preventable Cancer

1 THE POTENT PROMISE AND THE ROTTEN REALITY

She was my last patient of a busy morning. Her morning call to our clinic – "my bleeding just won't quit" – earned her the 11:40 a.m. slot, held open for patients with urgent matters. Her name was Susie.

As I would later learn, Susie was forty-six years old but hadn't seen a nurse or doctor for seven years. She'd moved around from state to state a few times, been briefly employed in the service industry, but never stayed in one place long enough or earned enough to qualify for ongoing medical care. The last place she'd gone for care, a community health clinic in Colorado, had offered subsidized care, but funding issues had forced it to close.

Like many women, Susie never put Pap smear appointments high on her list. "I should go get a check-up," she'd thought to herself. But such *shoulds* are rarely enough for patients like Susie to overcome daunting obstacles, including expensive medical fees, difficulty finding a clinic reasonably close to home, and perhaps most of all, the ability to trust a doctor with such an intimate procedure. Susie had been sexually assaulted. Women already feel vulnerable sitting on an exam table covered only by a sheet, knees spread apart for an internal pelvic examination – such vulnerability can be unimaginable for a woman who has experienced sexual violence.

Ideally, medical clinics offer patients a sense of safety, lessening their ambivalence about important exams. Our examination rooms in this clinic were small, equivalent to the interiors of Volkswagen vans. They held four-drawer, waist-high storage

cabinets whose compartments hid pieces of equipment that could make women anxious, especially the metal speculums. Shaped like a duck's bill, a speculum enables examiners to gently hold the vaginal walls in place for viewing the cervix – the vaginal opening to the uterus. The examination tables in our clinic were positioned to offer privacy, with the foot of the table farthest from the door. Fuzzy, colorful footies covering the stirrups where clients rested their feet provided extra padding and a sense of comfort.

Unfortunately, none of these factors made much difference in bringing Susie to our clinic – a woman from out of town, who, for a variety of reasons beyond her control, had waited too long to take advantage of the clinic's preventative cancer care. It didn't help that on that busy clinic day I'd had less opportunity to prepare for a patient like Susie. I'd only had time to read my medical assistant's brief note, telling me that Susie had had "no medical care for seven years," "irregular vaginal bleeding for three months," and a "swollen right leg for six weeks."

As I stood outside the exam room where Susie was waiting, my assistant approached me. "I did not want to write this on the chart," she whispered, "but the room really smells." I waited for more. "Susie told me she's scared something is really wrong."

When something is wrong, the patient is often the first to know.

The Moment Medical Training Rarely Prepares You For

As I cracked open the door to the exam room, the odor rushed out and overtook me. It was the smell of rottenness, the pungent smell of tissue dying. I knew that smell. As I listened to Susie's story, I sensed the diagnosis even before doing the exam: cervical cancer.

The odor was not lost on Susie. She sat in a chair beside the exam table, her face red, her eyes toward the floor. It occurred to me that her shame was probably one reason she'd waited so long

to go to a doctor, hoping her condition would improve before she had to have an embarrassing, traumatic examination, her vagina smelling of rottenness. But her condition did not improve. She told me she'd thought the smell came from bleeding for so long.

I asked Susie to tell me more about her leg swelling. *Only swollen on the right. Gradually getting worse. No, no calf pain* that might go with a blood clot but a generalized ache, *especially at the end of the day. Maybe some back pain, worse, also, on the right side of the back.*

As I listened, I carefully considered how to do this examination in the least distressing way. I was 99 percent sure I'd find a mass at the top of her vagina and that I'd want to take a biopsy to confirm what my heart and gut were so sure of already. Since Susie had been bleeding for so long, I'd also need to prepare for increased bleeding with the biopsy. Should the bleeding become heavy, I'd need to ask for help.

By now, Susie's morning appointment had wound into early afternoon. I told her I'd need consent for the biopsies. Susie's back stiffened, and she leaned forward in her chair. Her lips tightened, and I could see her brow knitting. As I got up to leave, I felt her anxiety. It had a presence, hanging thick in the air, mixing with the pungent odor.

Our clinic was on lunch hour, so I gathered up the necessary equipment by myself, and peeked into our medical provider room. My colleague, Samantha, was sitting there typing away. "Sammie, I'm about to do a biopsy on a woman, and I'm afraid she could bleed a lot. Can you please come in the room with me?" Sammie rose with a quick nod. As she opened the door to the room where Susie waited, we were again greeted by the odor. *That odor*. Sammie turned back to me with empathy and a knowing look in her eyes.

I introduced Sammie to Susie. While Susie lay on the exam table and I positioned her in the stirrups, Sammie held Susie's hand and talked to her in her beautifully calming, Southern drawl. I placed the speculum in Susie's vagina to see where the cervix sat. There it was, the source of the rotten flesh smell and some of Susie's bleeding: a dark-brown, rough-edged growth in such stark contrast to the smooth, pink, healthy tissue

surrounding it. Sammie and I made eye contact. With a subtle nod, I confirmed the diagnosis we'd both been expecting. I quickly obtained biopsies and applied silver nitrate to stop the bleeding from the missing tissue.

After removing the speculum, I conducted a bimanual examination on Susie's pelvic structures, as well as the bones lining her pelvis. Using two fingers, I felt a hard, irregular mass occupying the upper region of Susie's vagina. Placing one hand on her abdomen, I could feel the mass extending to the bones bordering the pelvis on the right side. I knew her tumor had likely spread beyond her cervix and her vagina. It had also cut off the lymph channels draining liquid out of the leg, which explained the swelling. As I finished the exam, Sammie fixed Susie with her warm gaze and told her how happy we were that she had come to see us that day.

The Deadliness of Delaying Care

I left the room as Susie dressed and took a few moments to close my eyes and breathe deeply to compose what I would say. Frankly, I needed to collect my thoughts by clearing the smell from my nostrils and the image of that irregular, oozing, dark mass. I returned to the room. "Susie, I did find a growth at the top of your vagina," I told her. "We won't know for sure until the biopsies return, but I'm worried it may be cancer, and that it may have spread outside your cervix." I stopped. I tried to allow my words to sink in. We sat together in silence. She started to weep. I passed her tissues and reached out to grab her hand. She would not remember most of what I was saying, but I hoped she'd remember my touch.

"Susie, there is treatment for this." Again, I paused, waiting for her to wipe her tears and return my gaze. "I have some excellent partners who specialize in caring for women who have cancer of the cervix. We will get you help." I was thinking that her treatment would mean chemotherapy and radiation, and that because the cancer had spread outside her cervix, her chances for a cure were lower, but still reasonable. When I share

such a frightening diagnosis, patients usually ask for information or help, but some can't speak at all because I have confirmed their worst fear, the fear of facing what their instincts already know. This fear can keep people out of doctors' offices altogether. Now that Susie had come to see me, I wanted to do everything I could to keep her coming back and get the treatment that could save her life.

After getting Susie's contact information, I walked her to the waiting area. "I will call you tomorrow to see how you are doing or if you have more questions," I told her. "You do not have to go through this alone."

It was now 1:15 p.m., and afternoon clinic was starting. I slumped onto a stool in a quiet room for a few minutes. I'd encountered something heartbreaking, but sacred. I'd entered a space with Susie where time stopped and everything that came before fell away. I felt complicit, somehow, in Susie's suffering. By uttering the word *cancer*, I'd rewarded a patient for finally seeking care by confirming her worst fear. Tears ran down my cheeks, thinking about Susie, how much her life had changed in the last hour. Did she hear any of the hope I tried to offer?

When she came to the clinic that morning, Susie had reached a crisis point in her health. As I confirmed her fear that "something was really wrong," I, too, echoed those words to myself. *Yes, something is really wrong.* Another patient had received a devastating, possibly terminal diagnosis for a disease I knew to be preventable.

The fact that science had recently deemed her disease preventable offered few reassurances for Susie. She came to a clinic in a country with sophisticated health care systems and resources, and she still ended up with advanced cervical cancer.

No Country Is Immune to the Ravages of Cervical Cancer

Susie's story starts to unpack the uncomfortable truth. Even in the United States, where we can offer vaccines that prevent cervical cancer and tests that can screen and treat for the first