

PART THREE

ACCEPTING



CHAPTER 5

Tómatelo a Pecho

The birth of an idea

I tried to celebrate life during the day, but the nights were long, frightening, and exasperating. Waking up in the morning was even more upsetting than trying to go to sleep at night, I awoke in a thick fog of fear, and it would take a few moments to clear my mind, remember why I was afraid, and control my emotions.

I was anxious about the future and terrified of the chemotherapy. During the day, I had ways of keeping my mind occupied, but at night, all my tactics failed. I was unable to calm myself down. I so dreaded the first moments after waking up that I found myself unable to fall asleep. Often, I got up and walked back and forth throughout the house in an attempt to exhaust myself.

Actually, walking and being in near constant motion became a way of life that has remained with me to this day. Day and night, I still have trouble sitting or lying still for any extended period of time.

Throughout those long and difficult nights, I had one constant companion. Kalah, my black German Shepherd, followed me everywhere. For many years, Kalah helped steady me in ways that no other friend could, valiantly fighting degenerative bone and heart disease to be able to keep walking at my side. In the spring of 2012, I finally lost my dearest walking companion. I still take long walks, most recently in a forest in Sudbury, Massachusetts, and I still pace the house at night. And, as I walk, every day, I am conscious of how deeply I miss Kalah.



Physical exercise has been an escape valve for me since my mid-twenties. I learned to use it to cope with anxiety while I was trying to finish my doctoral thesis in economics – on the challenging and unusual topic of Colombian street children and child labor.

Most weekends, taking advantage of the lovely weather in Cuernavaca, the ‘City of Eternal Spring’, I would go jogging or for a long walk. This was my time and space to be alone with myself and think, neither of which I could easily do in Mexico City because of pollution, traffic, and safety issues.

Tormented by a long night of pacing the house, bandaged-up but determined, I went for a long walk that Sunday. I hoped that exercise might help to clear my mind, wear me out, and make the nights easier.

As always, I took music to listen to, but I knew that this was not going to provide enough of a distraction, and I feared the direction my thoughts might take. Indeed, as I left the house, my mind raced back and forth between the mastectomy and the chemotherapy.

I was drowning in feelings of frustration, pain, loss, confusion, and above all, fear of the treatment I would have to undergo. At times, I would lose all sense of self-control and start to sob as I walked along the street. Every time I felt myself letting go I would start jogging, holding tight to the left side of my body. Rubén had asked me to avoid strenuous exercise, especially after the fluid formed in my armpit. But I could not stop myself from jogging because the pain of the exercise helped to take my mind off the fear. I mostly walked, occasionally violating medical orders and breaking into a run, for at least 30 minutes.

All of a sudden –and that is exactly how it happened, suddenly– a different thought popped into my mind and took over the mental space that had been devoted to feeling miserable about myself. I began to imagine the situation of another woman. As I walked, I thought about a scenario very different from the one I was living. I put myself through the mental torture of ‘hypothetically’ not being able to access treatment for my cancer. My own situation seemed awful to me. But the scenario I imagined was immeasurably worse, which paradoxically made it both horrifying and comforting.



I thought about a woman with the same diagnosis as the one I was facing, but with a starkly different life. She was poor, as is true for most women who inhabit our world. She was without resources, without insurance, a single mother and the head of her family. She was a woman like me – diagnosed with breast cancer at 41, and with small children. Yet, the decision she faced was not whether or not to accept chemotherapy. No. She was in her house with her mind spinning over how to finance her healthcare, worrying about who would take care of her children and her elderly mother. Or, perhaps, if she did indeed have access to treatment, as indeed was by then the case for an increasing number of women in Mexico thanks to the *Seguro Popular*, she was worried about how to pay for her children’s school books because she would have to spend her money on transportation back and forth to a hospital in Mexico City. Worse, she was terrified, not of the chemotherapy, but about who would take care of her three-year-old when she had to spend nights away from home getting the treatment she had been told she would need but did not understand. She tried not to think of her family’s income, but she knew she would not be able to work much for several months and would have to borrow money somehow. Every so often, she could not help wondering who would take care of her children if she did not survive.

Most likely, the father of her children had already abandoned her, leaving her struggling to make ends meet without any financial support. If by chance he happened to still be around, she anguished about when he would leave her, since he could not stand to see the mastectomy that she had undergone – in her case, with a single surgery. Though she detested it, she had become accustomed to living with the machismo that permeated her community, reducing women to no more than breasts and reproductive organs.

These thoughts were torture to me. The injustice – the realization that I had access to the most effective treatments, and she did not – nauseated me.

Months later, when I gave my first public testimony about my breast cancer experience, I expressed it this way: “The only thing worse than having chemotherapy is to need it and not be able to



get it; either because you cannot afford it, you have no insurance, or you have no way of caring for your children while you are in treatment. It is fundamentally disturbing to me –as it should be to us all– to know that *I do* have access to health care and that other human beings with similar needs do not. It is inequitable, unjust, and unethical.”

For the first time in my 20-year career working in health in developing countries, I was finally able to imagine, to force myself to try to *feel*, the terror experienced by a patient who cannot afford care. This is how I finally came to see myself as fortunate, even lucky, in the face of a diagnosis of invasive breast cancer.

I am Canadian. In my country of origin, all residents are covered by publicly-financed, universal health insurance. Canadians take great pride in having this kind of insurance, even, or perhaps because, we all share in the costs through high taxes. We consider it an integral and essential part of our social welfare system, as do most, but not all, high-income countries around the world.

I believe that denying someone healthcare services because they cannot pay for them or because they do not have insurance through their job is neither logical nor ethical. These were the convictions that had for decades inspired my work, and as a health economist I had come to learn that underinvestment in health is not only unjust, it also has negative effects on economic growth and development.

I had applied these convictions and knowledge for many years, and especially alongside Julio in support of the *Seguro Popular*, yet I had never had to live any of what I had preached. Thanks to my breast cancer, I was finally able to at least sympathize, although not really empathize, with poor families who desperately seek healthcare. I was experiencing the health system from a totally different viewpoint – as a patient. This gave me the ability to feel, in a more genuine and personal way, the pain and desperation that people and families who lack financial resources and health insurance face when they are confronted with the need to seek treatment for a serious illness.



That day in November of 2007 in Cuernavaca, I could not have imagined any of this. As I mentioned, I was not fully cognizant that *Seguro Popular* already covered breast cancer. Thus, I did not realize that the 41-year old Mexican woman with young children that I was imagining actually had financial protection through *Seguro Popular*. Likely, she did not know it either. Though through *Tómatelo a Pecho* and many other organizations we try to spread awareness, many women still do not know about their rights to health care.

Only a few years later, I was confronted with this reality and with the vast differences between health care in Mexico and the United States through the case of a very young woman, Abish Romero Juárez. Her case came to my attention through colleagues at the Dana-Farber Cancer Institute who were concerned about not being able to help her get access to treatment. At age 23, Abish was a legal resident in the U.S., working as a nanny in a home near Boston. She was diagnosed with breast cancer and convinced that this meant she had to leave her job, lose her insurance, and return to her home in Mexico City. I managed to get her phone number and reach her the night before she left to return to Mexico. She explained to me that she had found a lump through self-examination. Mammography and a biopsy had confirmed that she had breast cancer and that lymph node involvement was likely. I tried to convince her to stay in Boston and that I would help her to get an appointment with local experts on breast cancer among young women. Abish insisted that she had to leave because she had already resigned from her job and because she needed to be with her father and brother. I began to suspect another layer of breast cancer in the family and shuddered as she then shared that her mother had died two years before of the same disease. Abish then told me that she feared the costs of treatment and what it would mean to have her father try to pay for her care. Suddenly, I felt extremely empowered. I assured and reassured her that as soon as she touched ground in Mexico *Seguro Popular* would guarantee that she had financial protection and access to the best care, the same type of care that I had received and that she required.



In Mexico, she would receive the protection and care that she could not access in the United States. The contrast was stark and amazing. Never had I felt so proud of a project I had worked on as I did that afternoon. And indeed, Abish received excellent and extensive care at Mexico's *Instituto Nacional de Cancerología* (National Cancer Institute). Almost two years have gone by since that first telephone call and Abish has completed her chemotherapy and a double mastectomy and is doing extremely well. She is now working with *Cáncer de Mama: Tómatelo a Pecho*. She has become an advocate—in English and in Spanish—not only for women and the cause of people affected by breast cancer, but also more broadly for the need to provide social insurance for health that covers chronic diseases such as cancer.¹

That morning of November 11, 2007, I kept walking and began to design in my head the project that would become the program *Cáncer de Mama: Tómatelo a Pecho*. I reflected on what I had already learned from my own experience, especially the power of information and the importance of respectful treatment. Above all, I thought it imperative for every woman to have the timely detection that is essential for saving her life.

Just thinking of the potential of such a program made me feel better. I was infused with enthusiasm for a mission and a cause that I could take on and defend. For the first time since the mammogram, I was able to perceive some benefits from the burden of my disease and my personal suffering: I could learn from my own experience and apply my knowledge to helping others.

As I walked and the program began to take shape in my mind, I realized, much to my surprise and great pleasure, that I

1. Interviews in English and Spanish are available at: <http://www.tomateloapecho.org.mx/> and <http://www.youtube.com/watch?v=BPC8MgylFhI>. Romero Juárez A. Testimony. In Knaul, FM, Frenk J and Shulman L for the Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries. *Closing the Cancer Divide: A Blueprint to Expand Access in Low and Middle Income Countries*. Boston, MA: Harvard Global Equity Initiative, 2011. Available at: <http://gtfcc.harvard.edu/icb/icb.do>. And stories that inspired included in Knaul FM, Gralow R, Atun R, Bhadelia A. Eds. *Closing the Cancer Divide: An Equity Imperative*. Based on the work of the Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries. Cambridge, MA: Harvard Global Equity Initiative, 2002. Distributed by Harvard University Press.



was feeling less desperate. For the first time in weeks, I was thinking ahead, and thinking positively.

It was time to turn around and head for home. I had walked quite a distance from our home on *Privada Bel Senda*. Now, I wanted to get back to our house –*Casa Aviva*²– as fast as I could despite the pain in my chest. I was eager to present the idea of the new program on breast cancer to Julio, since the prospects for successfully proposing a project and obtaining financing depended in large part on him.

I think I surprised him when I arrived. I had been gone for well over an hour. I left the house feeling pain, sadness, desperation, confusion, anguish, and anxiety. I returned with a new attitude, and I imagine that I must have looked as much better as I felt. The determination must have shown in my face – *otro rostro* in Spanish.

When I came bounding across our garden to where he was sitting, a spring in my step, and announced that I, that we, were going to begin a national program on breast cancer, he really had no other option but to say, “Yes, we can.” It was our wedding anniversary – there was no way he could say no to me that day.

It was Julio who had the brilliant idea of naming the program *Tómatelo a Pecho*. This colloquial expression means ‘take it seriously’, and that was precisely the message we wanted to project to Mexican women, as well as to the health sector, decision-makers, and society as a whole. At the same time, *pecho* means breast, making the name especially appropriate for our project.

At the time of my diagnosis, I was working as senior economist at the Mexican Health Foundation, and also with Julio and Roberto Tapia on designing the programs of the newly created CARSO Health Institute (now the Carlos Slim Health Institute). The Institute had just been officially launched, and at that very moment, the 2008 work plan was being developed. The timing was ideal. I decided to propose, organize, and request funding for a program on breast cancer.

2. Many of the houses in Cuernavaca have names. Ours is called the House of Spring. *Casa* means house in Spanish, and *Aviva* means Spring in Hebrew.



I had my work cut out for me. I knew it was up to me to develop a solid proposal and design for a project that would reach people across the nation and that had the potential to have a real impact both on the lives of women and on the trajectory of breast cancer in Mexico. This new challenge was the best medicine that could have been prescribed for me. It gave me something constructive to occupy my time with and allowed me to take a very different attitude toward learning about and treating breast cancer.

Previously, peeling away the layers of ignorance about breast cancer, about my altered-self, had only exacerbated my fears. But that was when the information was only about *me* and about what I was going to face. Now, suddenly, learning about breast cancer had a different meaning. Instead of reading about Felicia and what could happen to Felicia, I could analyze the evidence and try to understand what it meant for millions of other women. The search for ways to empower other women gave me the opportunity to empower and educate myself. Informing myself turned out to be a powerful weapon against fear that enabled me to face the decisions I had to make about my own disease and treatment.

At the launch of *Tómatelo a Pecho*, four months later, I expressed my feelings about empowerment through information as a call for women to fight for our right to be informed patients:

I am fortunate because I had access to the information about my illness that allowed me to learn and participate in the decisions about my treatment. For many women, accessing and understanding the evidence about breast cancer is daunting. Facing and internalizing the evidence is even harder. Yet, educating yourself provides access to treatment options and empowers you to make decisions. It is both our right and our obligation, as women and as patients, to understand our health and our disease.³

My first task was to undertake research to better understand the epidemiology of breast cancer, the options for treatment, and the demands that they place on health systems. I eagerly began to put

³. Knaul FM. Inaugural Speech. Breast Cancer: *Tómatelo a Pecho* (Take it to Heart). *Proceedings from the launch of the program*, Mexico: Instituto Carso de la Salud, 2008. Available at: <http://www.tomateloapecho.org.mx/Archivos%20web%20TAP/54%20ProceedingsFromLaunch.pdf>.



together a literature search and a bibliography. I quickly located excellent materials, freely downloadable from the American Cancer Society, that enabled me to compare the situation in the United States with that of Mexico and the rest of Latin America.⁴

That same day, I began to contact colleagues who work in the field of women and health. The first person I wrote to was Ana Langer, a friend to me for more than a decade and to Julio for more than two. Ana is a world leader on issues of reproductive and women's health. She worked on these topics in Mexico for many years before becoming president of a renowned international civil society organization, EngenderHealth, and more recently a professor at the Harvard School of Public Health, where she leads the flagship Women and Health Initiative.⁵ I emailed her to discuss the idea of my nascent *Tómatelo a Pecho* project, as well as to inform her of my breast cancer.

I am so glad I was able to reach out to Ana. Her ability to listen, understand, and console me made her one of the people to whom I would turn most often and most openly in the months to come to confide my concerns, my feelings, and my dreams. When she answered my first email, I also learned that by chance, and to my great fortune, Ana was going to be in Seattle the following week. This meant that I would have a wise and caring friend with whom to share the results of my appointment with Dr. Julie Gralow.

I also wrote to one of the best epidemiologists in Latin America, Dr. Rafael Lozano. The evidence he was able to assemble demonstrated conclusively that breast cancer represents an enormous challenge for women, for their health, and for health systems. The incidence and mortality figures were astounding and worrisome, clear indications that the need to begin a program such as *Tómatelo a Pecho* was real and urgent. Before we studied the data, we had no idea that breast cancer was such a huge, and largely ignored, health priority in Mexico.

4. American Cancer Society. *Breast Cancer Facts & Figures 2011-2012*. Atlanta: American Cancer Society, Inc, 2011. Available at: <http://www.cancer.org/Research/CancerFactsFigures/BreastCancerFactsFigures/breast-cancer-facts-and-figures-2011-2012>.

5. Harvard School of Public Health Women and Health initiative. <http://www.hsph.harvard.edu/women-and-health-initiative/>.



The global reality of breast cancer is indeed shrouded in myths that stand in the way of effective responses to reducing the lethality of the disease. It is commonly and incorrectly assumed, for example, that breast cancer is a disease of women who are older, rich, and white. But breast cancer is, in fact, an equal opportunity disease that knows no boundaries, attacking women of all social classes, ethnicities, nationalities, and ages. Contrary to popular belief, breast cancer is not an illness concentrated in high-income countries. More than half of all cases and deaths occur in low-income countries. Nor is it a disease that attacks only post-menopausal or elderly women. For reasons that go beyond demographics and are still not completely understood, breast cancer is more common among younger women in low-income populations. In almost all Latin American countries, more than 50 percent of cases are diagnosed in pre-menopausal age groups – when the disease is likely to be especially aggressive. Indeed one of the facts that we uncovered with our research, and perhaps the one that shocks me most, is that as of 2006, breast cancer was the second most common cause of death in Mexican women between 30 and 54 years of age.⁶

In the face of this enormous challenge to the health of women throughout the world, our research also highlighted an encouraging message for the future: breast cancer is almost always curable if it is detected early. According to the American Cancer Society, and based on data from the United States, five-year survival is 99 percent for localized disease, where tumors are confined to the breast, and 84 percent for regional disease, in which it has spread to surrounding tissue or nearby lymph nodes. But five-year

6. Knaul FM, Nigenda G, Lozano R, et al. Breast Cancer in Mexico: a pressing priority. *Reproductive Health Matters* 2008; 16 (32):113-123. Knaul FM et al. Breast Cancer: Why Link Early Detection to Reproductive Health Interventions in Developing Countries? *Salud Pública de México* 2009; 51(Supl 2): s220-s227. Porter P. Westernizing Women's Risks? Breast Cancer in lower-Income Countries. *New England Journal of Medicine*, 2008, 358, 213-216; Knaul FM, Gralow R, Atun R, Bhadelia A. *Closing the Cancer Divide: An Equity Imperative*. Based on the work of the Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries. Cambridge, MA: Harvard Global Equity Initiative, 2002. Distributed by Harvard University Press; and, International Agency for Research on Cancer (IARC) <http://globocan.iarc.fr>.



survival plunges to only 23 percent for women suffering from distant-stage cancer that has metastasized to other organs.⁷ Still, this message of hope has yet to reach women, primary health care providers, and the majority of officials who design health policies in low- and middle-income countries.

Most women, and especially poor women, lack information and access to preventive healthcare. Very few manage to have regular screening mammography, and the vast majority –almost four out of every five women in the case of Mexico– do not have annual clinical breast examinations. Yet, this is a simple, non-invasive check-up that requires no infrastructure or machinery and that could –and should– be done effectively and respectfully as part of annual medical check-ups.

Because that level of basic, primary care is not widely available, only about one in every ten cases of breast cancer in Mexican women is detected in early, localized stages, when the probability for cure is so much higher.⁸ Late-stage diagnosis is especially common among poor women. There is a cruel irony to this: Mexican women have access to treatment through *Seguro Popular*, yet almost always arrive too late for this care to guarantee their survival.

As I have already shared, my decision to establish *Tómatelo a Pecho* was born out of my personal experience and convictions – my own experience with breast cancer and my firm belief that all patients have the right to be able to access the health care they need and to be protected from catastrophic health spending. Yet, the justification for the program came from overwhelming evidence that demonstrated that women are dying unnecessarily.

I was infused and energized by the realization that we had uncovered an evidence-based priority that long had been neglected by the health system. I imagined breast cancer as an enemy that had crept silently into the bodies of Mexican women and remained

7. According to the American Cancer Society's *Breast Cancer Facts & Figures 2011-2012*, local-stage tumors are confined to the breast, regional stage have spread to surrounding tissue or nearby lymph nodes and distant-stage cancer has metastasized to other organs.

8. Knaul FM, et al. 2008; Secretaría de Salud, *Programa de Acción: Cáncer de mama, 2006-2012*. México D.F, Secretaría de Salud, 2007.



there, hidden like a phantom. It was imperative to dispel the many myths that revolved around breast cancer and explain that it is not a disease reserved for women in high-income countries, nor for the rich, white or elderly. *Tómatelo a Pecho* generates and disseminates evidence to dispel these myths and help women to protect themselves and access healthcare.⁹

I summarized these convictions at the inauguration of *Tómatelo a Pecho* in March 2008 in Mexico City, the day before my third dose of chemotherapy, bald and proud:

“Much of what makes me feel fortunate in the face of this cancer, in the face of a mastectomy, and in the face of chemotherapy, is not available to most of the world’s women, including Mexicans... Yet, today I do not feel powerless before my illness or in the face of the responsibility to fight against it... We have answers for controlling this disease. We have solutions for treating it. Our responsibility is to make these solutions accessible to all Mexicans.”¹⁰

Juanita

Two years later, I met the woman I had imagined during the walk in Cuernavaca that gave birth to *Tómatelo a Pecho*. It was on the visit to *Hospital de la Mujer* in Yautepec that I have alluded to in early chapters. I was with Dr. Julie Gralow, my oncologist about whom you will read more later on.

We were taken on a tour of the hospital and it was then that I re-encountered the women who had first sounded the alarm about my cancer. First we were shown the new digital mammography machinery, and when the technician emerged from the examination room, and as I have already shared with the reader, I was dumbstruck by her face until I finally recognized her as the

⁹. Cancer de mama: Tomatelo a Pecho. <http://www.tomateloapecho.org.mx/>.

¹⁰. Knaul FM. Inaugural Speech. Breast Cancer: *Tómatelo a Pecho* (Take it to Heart). *Proceedings from the launch of the program*, Mexico: Instituto Carso de la Salud, 2008. Available at: <http://www.tomateloapecho.org.mx/Archivos%20web%20TAP/54%20ProceedingsFromLaunch.pdf>.



woman who had first diagnosed my tumor in the small, private clinic in Cuernavaca. I shared with her that she had helped save my life. Together we walked up a flight of stairs where I was greeted by a group of women who had survived breast cancer and were painting traditional Mexican shawls as a way of raising funds.

Next, we were taken to visit a woman who had recently started chemotherapy. This small hospital had no dedicated infusion area, and the woman was lying in a hospital bed covered by a sheet. One side of her chest was much larger than the other, and I too quickly seized the opportunity to reach out and try to help her to deal with the loss of a breast. I held her arm and said to her in Spanish, “Don’t worry you can manage mastectomy. I did.”

She was about 40 years old, dark skinned, somewhat overweight and I knew she came from a poor community not too far from the hospital. She looked up at me from the bed and with a bewildered look, asked, “What is mastectomy?” To which I replied, assuming I was explaining the term but not the outcome, “The surgery to remove the breast with the cancer.”

She, let us call her Juanita, replied, “I have not had any surgery. Just this red liquid they are giving me in my arm. But I am worried about how to pay for all of this because we are poor.” I tried to recover my poise and talk to her about *Seguro Popular* and convince her to go to Mexico City—about 2 hours away by car or bus—where her treatment would be covered, to which she replied, “I can’t afford to travel to D.F.¹¹ Even if I could, I have two little children, and no one to take care of them while I am gone.”

I was shocked. I realized that what I had thought was her breast was actually her tumor; my guess was that the cancer was about the size of a large orange. The surgical oncologist who was treating her then explained to Julie and I, “Juanita arrived with a large tumor in her left breast and lymph node involvement. But, it was not the tumor that made her finally seek care – it was the fact that she was having trouble moving her arm because of the swelling. We want to get her affiliated to *Seguro Popular* but she refuses to travel to Mexico City so we are trying to help her as best we can here.”

¹¹. D.F. is short for Distrito Federal and is another name for Mexico City.



I wanted to vomit.

I assaulted myself with questions: “How could the entire, expansive primary care network of the Mexican health system have failed so terribly to get her to seek medical care before her cancer got to this stage? How did we not detect her cancer earlier? How could she have been so ignorant of her health needs? Perhaps her husband had refused to allow her to be checked? Maybe she was afraid he would leave her and so hid the growth for as long as she could? Had she gone to a local clinic and been told it was an infection, as I later found out commonly occurs?” Finally, I asked myself, “What can I do to remedy this?”

Julie and I were ushered into the auditorium to give our talks to a group of about 200 patients and medical care providers. I was still shaken and trying to understand what could possibly have kept Juanita from seeking care for so long.

I finished giving my talk and there were many questions. One woman of about 50 raised her hand, stood up, took the microphone and looking straight at me said, “Why would I want to know if I had breast cancer? A woman without boobs is ugly.”¹² I realized I had not mentioned my mastectomy during the talk and that she did not know that I am mastectomized. I replied, “Do you think I am ugly?” She looked at me incredulously and said no more.

After the talk, she came to find me in one of the hospital offices to apologize and share with me that she had been diagnosed with breast cancer that morning. She had her husband with her – in fact he had been sitting next to her in the auditorium. I told her she had absolutely nothing to apologize for, but begged her to look at herself in the mirror and see that she was beautiful with or without breasts. If she did not believe she was lovely, who would?

I have shared this experience all over the world, and written about it many times. It was my meeting with Juanita and this visit to the *Hospital de la Mujer* of Yauhtepec that gave me the certainty that so much could, should, and can be done to prevent unnecessary deaths from cancer in low- and middle-income countries.¹³

¹² I translate directly from the Spanish, “Una mujer sin chichis es fea.”

¹³ Shulman L et al. Core elements for provision of cancer care and control in low and middle income countries. Chapter 5 in Knaul FM, Gralow R, Atun R, Bhadelia A, 2012.