



Beauty without the Breast



Felicia Marie Knaul

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*For Hannah Sofia and Mariana Havivah (Maha),
the anchors that stayed me through the storm,
for the many moments of inspiration, happiness,
and love they bestow upon me.*



CONTENTS

FOREWORDS	XIII
Dr. Julie R. Gralow	XV
Dr. Paul Farmer	XVII
INTRODUCTION	XXI

Part one: Doubting

CHAPTER 1 • Could it be...?	3
Mammogram at 40	3
The mammogram and the precipice	6
What is a BI-RADS?	12
I am not overreacting	16
Tell me I <i>am</i> overreacting!	21
Next steps; first decision	24
CHAPTER 2 • Pause to enjoy the world of the healthy	27
The wait	27
Disneyland... To go or not to go	32
Though it sounds childish: The magic of Disney	38

Part two: Knowing

CHAPTER 3 • It is	43
The biopsy: Now I know	43



Lunch in <i>Tlalpan</i>	49
One afternoon to get my life in order	53
Hannah's question	57

CHAPTER 4 • Meeting my altered-self 61

Becoming a patient	61
The first surgery	67
The first night	70
My mother	75
Next steps amid tribulations	78
Celebrate life as if you were healthy	84
Decisions, round one	88

Part three: Accepting

CHAPTER 5 • *Tómatelo a Pecho* 95

The birth of an idea	95
Juanita	106

CHAPTER 6 • A tempest of decisions 109

Facing my fear	109
The friendly tumor board	111
I am cancerous	116
My first, second opinion	120
Alone, for the first time	123

CHAPTER 7 • In search of answers 129

The trip to Seattle	129
A cancer hospital with a view of the bay	132



Some answers and more questions	134
Navigating the labyrinth	140
CHAPTER 8 • Time with friends	143
Decisions	143
Cushions	145
Moving forward	147
CHAPTER 9 • To mastectomize or not to mastectomize?	151
Confusion	151
My first MRI	154
Results and progress	157
A gift to myself: painting with hospitalized children	160
The second trip to Seattle	166
Radiation or mastectomy	168
I finally cry	170

Part four: Embarking

CHAPTER 10 • A farewell to health	175
Bridging the worlds of the healthy and the sick	175
Sky, sand, sea, and moon	176
The rock of singing seals	178
Mastectomy is right for me	179
Inner peace	183
CHAPTER 11 • The mastectomy	187
The surgery will be in Mexico	187



Presenting <i>Tómatelo a Pecho</i>	188
The mastectomy	190
I can do this	194
CHAPTER 12 • Facing Chemotherapy	199
Concentration camps and chemotherapy	199
Becoming a patient	202
With Maha's help	208
CHAPTER 13 • Preparing for chemotherapy	211
The wig business	211
Looking in the mirror	217
Breast 'inflation'	219
Acapulco	220
CHAPTER 14 • The first dose: FEC #1	225
The haircut	225
The day before	228
The day finally arrives	233
Chemotherapy begins	238
Unveiling the wigs	243

Part five: Learning

CHAPTER 15 • I lose my hair and rediscover myself	251
The loss begins	251
I decide to live life	253
Helping Maha to assimilate loss	257



Hair just keeps falling	259
With Hannah, I manage to end the endless hair loss	261
I develop a new identity	263

CHAPTER 16 • Life with chemotherapy 269

Coping strategies	269
Healing myself through exercise	272
Taking heart: opportunities to enjoy life	274
Finding inspiration	275

CHAPTER 17 • Expectations mold perceptions 283

My last dose of chemotherapy	283
Venturing back	284
Sepsis	287

Part six:

Surviving, living, and giving

CHAPTER 18 • Entering survivorship 297

Why survivorship	297
Life post-chemotherapy	302

CHAPTER 19 • Living survivorship 311

Some surprising improvements	314
Breast reconstruction ...an ongoing dilemma	320
Sexual non-health	328
Ongoing challenges	334
Living with the fear of recurrence	340



CHAPTER 20 • The many forms of prayer	345
I was blessed with many prayers	345
Giving back is a way of healing	349
A CHAPTER OF BEGINNINGS	355
Moments mean so much more	355
Feeling health	355
To loving life	358
EPILOGUE • The partner's perspective: four love letters. Julio Frenk	361

Bibliography & Websites

BIBLIOGRAPHY	373
WEBSITES	381

FOREWORDS



Little did I know where the journey would lead us when Felicia Knaul and I first met as patient and physician in 2007. My first impression, when I walked into the clinic examination room, was of a beautiful, poised, intelligent woman who was a bit frightened of me, and even more frightened of what I was about to tell her. Felicia was worried that she didn't know much about breast cancer or its treatments, but I found her to be quite well prepared for our visit and what was to follow. She understood the aggressive features of her cancer and had time before our meeting to emotionally process her diagnosis – although it is really impossible for anyone to fully prepare for the reality of chemotherapy, an effective but toxic necessity in Felicia's case.

She was adamant from the beginning that she wanted to receive the majority of her treatment in Mexico, to demonstrate confidence in the health care system that her husband, as Minister of Health, had helped build and one to which she had dedicated her career. She also envisioned a unique opportunity to show her Mexican countrywomen that a woman who loses a breast to surgery and loses her hair (albeit temporarily) to chemotherapy can still be confident and strong.

Felicia has completed treatment and is healthy and disease-free, but she is not without residual side effects that impact her daily life. The surgeries and chemotherapy were tough, but they had fixed dates and endpoints. She geared herself up emotionally and physically, got her support system behind her, and made her way through the treatments. And then, like most breast cancer survivors (and their family and friends), she expected to recover and go back to her prior life and health. But no one who goes through a cancer diagnosis and treatment is ever the same. In *Beauty without the Breast*, Felicia describes her transition from patient to survivor, expressing her surprise at how long the whole process of dealing with breast cancer can be. Her later chapters provide excellent documentation of the multiple ongoing issues a breast cancer patient continues to deal with for years after treatment ends. This concept of survivorship as a critical part of the cancer treatment continuum is only recently gaining acceptance in the US, and remains an unrecognized concept for many.



Flash forward to 2012 – who could have imagined where Felicia would be today? While still on chemotherapy, she founded *Tómatelo a Pecho*, dedicated to creating breast cancer awareness and promoting early detection in Mexico to save lives. After moving to Boston, she created the Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries, uniting experts in cancer, global health, health systems and health economics. She has published extensively and traveled the world to address health inequities and improve opportunities for cancer patients globally. Felicia’s role has evolved from cancer patient to passionate cancer advocate to respected leader in global oncology. I have been incredibly fortunate that she’s taken me along on her journey.

Felicia continues to courageously tell her personal story, very publicly and honestly, throughout Mexico and the world. Overcoming the obstacles of stigma, fear and machismo have not been easy, as I witnessed following a talk in Mexico. During the Question & Answer period, a woman in the audience told Felicia, “a woman without a breast is ugly” (I am told that the actual statement was much harsher, but they cleaned up the translation for me). Felicia’s calm reply was “I am missing a breast; am I ugly? A woman without a breast is no less a woman.” I watched the woman, her husband sitting next to her, and indeed the whole audience, process Felicia’s reply, as they slowly and very visibly accepted this statement as fact. Beauty without the Breast, that’s Felicia – and it is the perfect title for Felicia’s story.

Julie R. Gralow, M.D.

Jill D. Bennett Endowed Professor in Breast Cancer, Medical Oncology,
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Director, Breast Medical Oncology, Seattle Cancer Care Alliance



This brave and eloquent narrative is a clear-eyed account of breast cancer from a patient's perspective. My colleague and friend Dr. Felicia Knaul recounts her cancer diagnosis and treatment with admirable honesty, detailing her experience of breast cancer and its effects on her body and mind, her marriage, and her family while advocating for humane and efficacious treatment for women in Latin America and beyond. Her generosity may serve as a source of succor for fellow patients, and as a guide for their providers and loved ones.

Felicia's personal account also serves as the genesis story for the significant research and advocacy work she has undertaken. Throughout her experience of breast cancer and the writing of this book, Felicia was acutely aware of the difference in experience and access to care (and cure) between a patient like herself (as chief economist of the Mexican Health Foundation, she was a colleague of her doctors) and a poor patient with little information about her illness and scant chances of determining the course of her own care. She also contrasts the support she received from her husband, another dear friend and colleague, Dr. Julio Frenk, with the rejection and abandonment associated with the disease that she had witnessed in her work promoting early detection among poor women in Mexico.

Remarkably, Felicia and Julio developed the '*Cáncer de Mama: Tómatelo a Pecho*' program concurrently with her chemotherapy treatment. In Latin America, where poor women make up a significant percentage of breast cancer patients, the organization has done much to disseminate information about prevention and treatment, to elucidate the burden of non-communicable diseases on families and on the public health authorities in developing countries, and to address stigma.

Felicia's own illness led her to a deeper understanding of how poverty and gender inequality lead to tardy (or missed) diagnoses, poor-quality care, and a lack of follow-up. She details the physical sequelae of her surgeries and chemotherapy, as well as their psychological and emotional impact on her and her family. She recounts her initial fear at hearing the word 'oncologist' and her



initial resistance to chemotherapy, as well as her struggles with body image and self-esteem following mastectomy and chemotherapy. And she links her own experience to a health economist's careful analysis of the disease, and to another call to action on behalf of women who lack access to timely diagnosis and effective and compassionate treatment. In short, this book is an appeal for accompaniment even as it serves as a form of it.

In 2010, Felicia and I, together with Julio and other colleagues on the Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries (GTF.CCC), published a call to action in *The Lancet*, one of the world's oldest and best-known medical journals. In that article we argued that much could be done to improve the treatment of non-communicable diseases, including many malignancies, and that some fairly straightforward strategies might make a big difference in the low- and middle-income countries where cancer will exact its greatest toll.

Beauty without the Breast offers that rare combination of an intimate account of a battle with cancer and an informed discussion of the policies that might lessen the toll it takes. Felicia Knaul makes compelling arguments for the social and economic value of preventive medicine, and of educating and empowering breast cancer patients within every social stratum. It is a narrative of enormous value for patients and their families, for doctors and other providers, and for those making decisions about the best way to offer cancer care to all those who need it.

Paul Farmer, M.D., Ph.D.

Kolokotronis University Professor and
Chair of the Department of Global Health and Social Medicine, Harvard Medical School;
co-Founder, Partners In Health

INTRODUCTION

PART ONE

DOUBTING



CHAPTER 1

Could it be...?

Mammogram at 40

In October of 2006, my gynecologist, friend, and colleague gave me medical advice that turned into a gift of life. I still do not know exactly how long this gift will last, but I am now certain that my years of healthy and enjoyable life will not be few.

At my annual check-up, Dilys Walker, who had been my gynecologist for several years, told me that having turned 40, and especially because I had uneven breast tissue,¹ it was time to start getting regular, annual mammograms. As part of the physical examination that I routinely had every year, Dilys carefully performed a thorough clinical examination of my breasts and found no anomaly. After completing the examination, she gave me a written order for a mammogram.

The recommendation to have a mammogram generated in me a mix of lethargy and anxiety. Although I knew of no history of breast cancer in my family and had no reason to suspect a problem, I confess that I was afraid. A routine mammogram is nothing to fear and should not have generated such anxiety. To this day, I have no idea why I was so afraid or if I sensed something was awry.

Since my youth, I have always been very conscientious about getting regular gynecological check-ups and insisting on a complete annual examination with a PAP test. I was obsessive (maybe even extreme), and would schedule an appointment with Dilys at least once a year and, if I could, every six months. If anything alarmed me, any anomaly, any problem, I would turn to her.

¹. For more information on the anatomy of the breast see: Love S & Lindsey K. *Dr. Susan Love's Breast Book*, 4th ed. Cambridge: Merloyd Lawrence Book-DaCapo Press, 2005.



For some reason, and uncharacteristically for me given how obsessive I am with my check-ups, I decided to hold onto that piece of paper from Dilys' prescription pad for one whole year and postpone the mammogram until just before my next annual check-up. I scheduled the appointment for my first routine mammogram for the last weekend of October 2007. I could never have suspected that for me this would be my first and last 'routine' mammogram.

I do not know if it made any difference that I delayed for a few months; in fact, it may have been a good thing, making it easier to identify suspicious images that perhaps would have gone undetected a year earlier.

What I do know is that I had enough training not to delay the mammogram too long. At the time, I had already accumulated two decades of experience working on health system reform in Latin America and globally. I studied health and development economics and have a doctorate in Economics from Harvard University. One of my areas of expertise is women's health. I also married into health. Dr. Julio Frenk Mora, my husband, held the position of federal Minister of Health of Mexico during the administration of President Vicente Fox, from December 2000 to November 2006.

Yet, in delaying my mammogram, I reacted as many women do and it is important to understand why I did. Women experience tremendous fear about mammography. Consequently, we tend to avoid having a mammogram despite the fact that it is, without a doubt, the best way to protect ourselves from breast cancer.

The tendency to avoid mammography is even greater if women have reason to suspect that the images will not be undertaken properly or interpreted correctly, that the results will not reach them, or that the test will not be administered in a respectful and dignified fashion. I later found out, as I heard the experiences of many women in Mexico and other developing countries, that a high-quality mammogram undertaken in a respectful manner—like the one I could fully expect to receive—is far from the norm. All too often, and especially for poor women and in lower-income countries, gaining access to effective mammography is a huge challenge.



In personal testimonies, women continue to share with me how they were left undressed for long periods of time, waiting in line to get a mammogram without any explanation about the test or why it is important, and then waiting several weeks or even months to obtain their results. Although there are several government programs and civil society organizations working to improve access to high-quality mammography in Mexico, it continues to be true that only a minority of women have the luxury I had: to decide when and where to have my baseline mammogram.²

In too many countries, even when women are screened or find a lump in their breast and seek medical care, they encounter a resistant and even hostile health system. Too many women with late-stage breast cancer have described to me how a physician insisted that a mammogram was unnecessary and that they were overreacting.³

The lack of responsiveness of the health care system is symptomatic of and exacerbates the gender discrimination these women probably face every day at home, at work, and in their communities, especially if they are poor. It is part of the stigma they will confront living with breast cancer, a disease directly related to their physical identity as women and to their reproductive health.⁴ I grew to understand this better when I began to try to teach low-income women in Mexico about the importance of regular mammograms. Many women, especially those who are poor, tell me they will refuse any type of screening mammogram because they are afraid of being abandoned if their partner thinks something is medically wrong with their breast.

2. Nigenda G, Caballero M, & González-Robledo LM. Barreras de acceso al diagnóstico temprano del cáncer de mama en el Distrito Federal y en Oaxaca. *Salud Pública de México* 2009; 51 (supl. 2): S254-S262.

3. In response, *Tómalo a Pecho* developed a training program with the National Institute of Public Health of Mexico supported by the Seguro Popular that is working with health promoters, nurses and physicians in several states. <http://tomateloapecho.org.mx/>.

4. Knaul FM, Grañó 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, 2012. Distributed by Harvard University Press.



Thus, my situation was very privileged compared to that of the majority of women living in Mexico. It would take months for me to recognize it, but I was lucky.

The mammogram and the precipice

Nothing foretells news that will transform your life. Nothing around you suggests that the morrow will be different, and that your life will take a radical turn for the worse. October 27, 2007, was a Saturday like any other.

Like many women, I juggle the difficult balance between the roles of wife, mother, daughter, sister, and professional, as well as having my own hobbies and interests. My face often reflects the stress and my eyes the desire, to double, triple, and quadruple myself so as not to face the frequent dilemma of being in one place while wanting or needing to also be in another.

That Saturday in October was no exception. The appointment for the mammogram was at 10:30 in the morning. My daughters, Hannah and Maha, had swimming and art lessons at home. I also had a meeting scheduled with my colleague, Gustavo Nigenda, who was coming over to the house with his two-year-old daughter.

Unfortunately, my mammography session was running over the allotted time because the technician insisted on taking extra images. This made me very nervous and worried. I had already put my shirt back on in order to quickly leave the doctor's office when the radiology technician came into the cubicle and shook me abruptly out of my thoughts. "Please undress again. We have to repeat some images."

"I'm running very late," I thought. "I should have called Gustavo to tell him we should meet at 11:15 instead of 11:00." I was frustrated and worried about the time spent on this routine medical procedure, one that I had assumed would take no more than 20 minutes. The concern about being late for my meeting, in fact, helped me by diverting my attention from the anxiety and fears that were growing as the number of images increased.



After taking several additional films, the technician asked me not to get dressed again because the radiologist would probably want more tests. My frustration mounted as I realized that I had spent much more time than expected at the clinic. The technician showed me out of the booth and sat me on a bench, still in the gown. I insisted that I had to leave, and she told me that the radiologist wanted to do an ultrasound.

I was alone, waiting outside the room where only minutes before I had my baseline mammogram. I did not want to spend any more time on a ‘routine’ examination, so I decided to call Dilys. I was already running very late, and somebody had to help me get out of that clinic.

“Dilys? So glad you answered your phone. I came to have that routine mammogram you asked for, but I am running really late. Gustavo is waiting for me at the house. Can you help get me out of here? Could you tell the doctor to let me go now? It always happens, but please tell them not to do anything special, you know, because I’m Julio’s wife.”

I asked the radiologist to please speak with Dilys –they knew each other– and handed him the phone. As I did this, I glanced over into his office where the images of my breasts were up on a backlit screen. Since I had never seen a mammogram before, I did not know there was anything abnormal or worrisome about some little dots of light that I saw near the nipple in one of the images.

There was a pause in the phone conversation. Time seemed to be passing more slowly. I became very uncomfortable. The rhythms of my surroundings had changed. I worried. “Why is Dilys talking to the doctor for so long?!” I bitterly complained to myself with a sense of frustration that quickly mutated into a dark cloud of fear and apprehension.

I began to think about all the times I had tried to do breast self-examination. Since my breast tissue was dense and irregular, every attempt left me feeling very anxious. To my ill-trained hand, all the tissue felt full of small, worrisome lumps. Those experiences were similar to the unpleasant anxiety assailing me at that moment in the clinic.



I remembered how, when I was about 20 and just a few years after my father's death from cancer, I was convinced that I had found a small, suspicious lump in one of my breasts. Extremely distressed, I immediately called my best friend, Renata Block. She, a woman much older than I, was the social worker who accompanied my family through my father's battle with cancer. Renata, who herself succumbed to cancer in 2004, was a person in whom I confided many things.

On that occasion in my early twenties, I went to see my gynecologist and found that there was absolutely nothing abnormal. That time, it was just me overreacting. This time, I could not call Renata and my thoughts turned to how much I missed my dear friend, as I still do, and to how all my losses of those closest to me had been to cancer.

I could not manage these thoughts. I realized that I would drive myself to panic. I forced myself to contain my mind firmly in the fear of the present.

I tried to calm myself down by thinking that I always exaggerate things; that this time was no different than when I was in my twenties. I went back and forth between chastising and consoling myself. "You've done everything right and you are only 41 years old. Aren't you still young? Of course you are. And this is a routine examination. You're a hypochondriac. You're a hyper-chondriac. You are a *super*-chondriac! There can't be anything wrong. That's why you always went to the doctor regularly. Because you had a lot of lumps and you were always scared when you touched your breasts trying to find something. So, of course, it's another cyst..."

The ideas were accumulating like drops of rain in a storm, one after another, while the seconds passed. Just as in a heavy downpour, they threatened to overflow the barriers that are built to contain them.

Suddenly, I remembered that my physicians had advised me to look for changes when I explored my breasts. I began to think about this and resumed the conversation with myself. "OK, let's remember if you noticed any change since your last appointment with Dilys. There was some dryness in the last few months, but this time it was a little different: over the areola and only on the left side.



But you went for a breast examination just a year ago and there was nothing,” I reminded myself. “The radiologist still hasn’t told you what they are seeing on your mammogram. Maybe they’re looking at the right side. Felicia, you are exaggerating,” I rationalized in silence, in a frenetic and useless effort to calm myself down.

Barely a few minutes had passed, maybe five, but it felt like eons of time had gone by. Something significant had changed. Nothing seemed routine anymore. Yet, and perhaps for the first time in my life, I simply wanted to be normal and typical instead of special or exceptional.

The radiologist handed back my phone. An awful wave of nausea came into the back of my throat, and spread down my esophagus, heading towards my stomach. I had a premonition that something very unpleasant was on the way. I perceived a worry that I did not want to hear in the tone of Dilys’ voice. Instead of lifting the dark cloud of doubt and fear, the cloud grew darker. “Felicia, let them do everything they think is necessary. I’ll see you afterwards here in my office. Bring your mammography films.” There were no more questions for me to pose. Dilys had said it all.

I suddenly realized that I would never arrive at the appointment with Gustavo at my house. In a matter of seconds, all else that was supposed to have happened that morning faded into the background. It all seemed part of another life, a life of normalcy so different from the one I was now being forced to enter. I teetered between realities –healthy versus diseased, routine versus chaotic– and began to lose touch with both. One was the life that I continued to try to hold onto, but that was quickly slipping away from me; the other was a new life, a new world, that I desperately tried to reject as not happening to me. I attempted to cope by trying to envisage the scene from outside of myself, as a spectator.

At the same time, I clutched onto simpler matters as a means of coping. I called Gustavo at the house and told him that there was a problem with the mammogram. To prevent myself from bursting into tears, I refused to go into any detail, despite his insistence. I told him to please make himself at home and start working; I would get there as soon as I could. I asked him not to say anything to the girls, and to have Maha play with Sofi as if nothing out of the ordinary was happening.



Despite my best efforts, I was not very successful at diverting my thoughts. I was thinking about so many things that I did not want to think about anymore. Worse yet, I did not really know *what* to think. I had no information. I remember it as the first moment of absolute terror fueled by uncertainty – perhaps the worst kind, as it is the fear of the unknown. The panic fed on itself and became increasingly profound and overwhelming, yet I could not show or release it because I was sitting in a clinic surrounded by strangers.

I continued to have the impression that I was my own spectator, watching from somewhere outside of myself. I struggled with an overwhelming feeling of vulnerability that was beginning to consume me. I saw myself as small and frail, naked from the waist up except for a gown that barely covered me, in the hallway of a health clinic, surrounded by a huge cloud of fear and uncertainty. This cloud was enveloping me, threatening to invade and take over the space where a healthy, determined woman had been only a few moments before. A cold sweat trickled down my back. And then the tears of fear finally started to pour out.

This was not the only time I would observe myself and judge my state of being as if I were a bystander. It was merely the first time.

Indeed, as I reread this book almost five years after those first, terrifying moments of learning to know my cancer, I am struck by the contrast of how I saw myself then compared to now. My first images of myself are as a frail and weak spectator. Now I perceive myself as a strong and stable person who wrestles with the disease. I am proud and grateful that I was able to heal from the inside out.

Yet, I still recall and can describe the feelings and sensations of those first moments. It was like falling off a precipice into an abyss, without knowing how the fall happened or how the firm ground that moments before had sustained me had suddenly disappeared from under my feet. I knew not where I found myself, nor the depth of the abyss into which I was falling. I had no sense of when I would reach the bottom, nor what I would find there. I could not fathom how, or if, I could escape from the hole I was falling into. As the hole grew deeper, I realized I had no idea what



tools I would have at my disposal for the long climb out, or where to look for escape routes. And as I fell, I feared never again feeling firm ground. Indeed, I had no sense of when I would hit bottom, or if, once I did, I would ever get back to the point from which I had fallen. In a tiny span of time, I had totally lost my bearings and had become utterly confused.

The sensations of falling off a precipice and plunging into an abyss continued for the next nine days. There were few moments of respite. For me, these days were my first encounter with the uncertain and the unknown, a shadow that today, however faint, I know will accompany me for the rest of my life.

The depth of this sense of uncertainty took me completely by surprise. It was the first of what would become many encounters, as I gradually accustomed myself to living with the fear of a disease – a new, uncomfortable, and unwelcome companion that is a part of the daily existence of those of us who live with a chronic and potentially lethal illness. Indeed, learning to make peace with the fear that the disease could recur is an essential part of survivorship, at least in my case.

To manage to live with the specter of uncertainty, I eventually developed a set of coping skills and strategies. The first was to *compartmentalize* my feelings. I packed my fears away into separate boxes, to be opened when, as, and if I found the emotional and physical tools to confront each one. If it were not for these coping mechanisms, I would face the specter every day with the same level of unbearable anguish that I describe above, and which at first threatened to overwhelm me.

Unfortunately, at that moment I was bereft of coping strategies and had no idea of how to package away my fear.



What is a BI-RADS?⁵

The radiology technician guided me to another room for the ultrasound. As the radiologist came out of his office, I looked straight at him for the first time. I was calmer now, and I wanted to get very clear answers about what was happening to me.

“I just found out who you are married to,” said the radiologist, “but, only because Dr. Dilys⁶ told me. Before her call, we had no idea. I want you to know that none of the tests we are doing are because Dr. Julio Frenk is your husband.”

And then he uttered the words that I still remember to this day, because with them I lost hold of that tiny space of solid ground onto which I had retreated, fell off the precipice and was catapulted into the abyss: “We are doing all this because there is a suspicious image, and we think you have a problem.”

“What side is the suspicious image on?” I asked him. “The left,” he answered. I remembered the secretion, and that I had gotten a bit scared when I noticed it months ago, but thought it was just dryness of the skin.

More terrible thoughts began to chase away the previous ones. I realized the nightmare was going from bad to worse and that I was wide awake. I started to cry from the fear, but quietly and just a little. I also cried at the paradox of standing before a man that I had never seen before, and who was now giving me such brutal news that would forever mark my life. The four words ‘you have a problem’ quickly became five in my mind: ‘You have a serious problem’.

While he was performing the ultrasound, the radiologist mentioned something about ‘bye rad’. I had no idea to what he was referring. I had never heard the term before. Later I learned BI-RADS⁷ is a way of grading tumors, and that my grade provided

5. Love S & Lindsey K, 2005.

6. In some parts of Latin America it is not uncommon to refer to a professional using their title and first name.

7. BI-RADS stands for Breast Imaging Reporting and Data System. See: <http://www.acr.org/Quality-Safety/Resources/BIRADS> for additional information on this much-used system for grading the severity of tumors.



sufficient reason to be very concerned. Very fortunately for me, this radiologist knew how to read a mammogram properly. He graded the image correctly—as highly suspicious—and sounded the alarm.

I would grow to feel much more afflicted by the BI-RADS term over the nine long days that followed, while awaiting the results of the biopsy.

It took me months to appreciate how fortunate I was to have been blessed with a relatively early diagnosis. An erroneous mammogram can literally be a death sentence, as it means losing precious time to a tardy diagnosis of the disease. Diagnosed early and treated, five-year breast cancer survival is today close to 99 percent. Yet, timely diagnosis is the exception rather than the norm in most parts of the world. The majority of women diagnosed with breast cancer in low- and even middle-income countries are in very late stages.⁸ Diagnosed late, even with appropriate and sufficient treatment, the probability of survival falls to below 25 percent.⁹

Indeed, there are few—maybe even very few—radiologists specialized in breast imaging in Mexico. I would remember this moment 12 months later, sitting in a public event of the *Asociación Mexicana de Mastología* (Mexican Association of Mastology), when I learned about the case of a woman whose breast cancer took eight years to diagnose. It was delayed not because she did not get her mammograms, but because they were interpreted incorrectly. I saw pictures of eight years of misinterpreted (or perhaps never interpreted) mammograms and a final diagnosis of invasive and advanced breast cancer with little hope of survival for the patient.

That October 27, completely ignorant of my fortune, I asked the radiologist, “Doctor, what does ‘bye rad’ mean?” He answered: “A BI-RADS of three to four is a mammography that suggests a high probability of a malignant lesion.” I insisted: “How high is the probability?” My voice trembled, and I repeated *howhowhowhow* or

8. Shulman LN, Willett W, Sievers A & Knaul FM. Breast cancer in developing countries: Opportunities for improved survival. *Journal of Oncology* 2010. Article ID 595167.

9. American Cancer Society. Breast cancer facts and figures 2011-2012. Available at: <http://www.cancer.org/Research/CancerFactsFigures/BreastCancerFactsFigures/breast-cancer-facts-and-figures-2011-2012>.



maybe *hhhhhow*. He answered, an unwelcome reply, “More than 50 percent. Perhaps 60.”

The radiologist marked and measured a lesion of 1-2 centimeters with the ultrasound device. The fear began to escalate and I thought I could hear it drilling a hole in my mind. Or perhaps it was my heart that I heard, now beating hard and rapidly. In front of my face, I saw a stain, a shadow, on the ultrasound screen. It was the mutilation produced by my *altered-self*—the term I would come to use to refer to my cancer.

I recall that the image of the breast lesion made me think of how, once before, I had seen a small spot on an ultrasound screen. That time was my first and only full-term pregnancy. The spot was the first photo we have of Hannah. The irony made the tears flow.

The words were booming in my head. “Probability of what? Of having something? What *something*?”

I suddenly understood. Heavy words fell down on me... “Of having a malignant tumor. Of having cancer.”

Once again I broke into a cold sweat, and my legs trembled as I realized the magnitude of the problem. The bad news I was hearing was about my body. I struggled to understand and asked myself incredulously, “How did I get to this point? How did this happen? What did I not see? I could not feel anything. There was no change in the skin of the breast. Just that little bit of dryness, but that was surely nothing.”

As I dressed, in my head, in my mind, I could not stop questioning and thinking about different scenarios. I was trying to understand what the probability really was of having cancer. Yet, I had very little understanding of my situation. I did not know the meaning of the technical or medical terminology. The information I had received was overwhelming. Yet at the same time, it was too little information. Contradictory, yet true. I knew I had a suspicious BI-RADS, a key piece of data that could mean pain, suffering, and death. Yet, this was only a tiny fragment of the complex information that would be needed to actually diagnose ‘the problem’.



When I called Dilys again, she said, “Felicia, come to my office immediately.” Once again, I perceived that ominous tone in her voice. I sensed that something catastrophic was happening to me.

By this point, I could not stop crying despite my best efforts to control myself.

Again I took refuge in everyday matters. I thanked the radiologist and asked him to forgive me for having resisted doing the ultrasound.

I would meet both the radiologist and the technician who had read my mammogram again, though several years later and in a very different setting. I was invited to speak to a group of women, many of whom were facing breast cancer, at the *Hospital de la Mujer* (Hospital for Women) in Yautepec, Morelos. This is a public facility located about one hour, by car, from the clinic where I was diagnosed. I was taken on a tour of the hospital that began with the mammography suite, because the hospital and the Ministry of Health of Morelos are striving to put in place better screening and diagnostic facilities for breast cancer. As I stared at the face of the radiology technician who came out to proudly show me the quality of the services being offered to low-income Mexican women, I realized that I recognized her from somewhere. But I could not understand why this brought a wave of terror over me. As I heard her speak and watched her facial expressions, I realized she was the same woman who had insisted and convinced me to have additional images taken of my breast in 2007. I made her recall my case and later that same day, I met my radiologist who was now also working at the public hospital. I share this story whenever I can. I am grateful that at least some women in Morelos have access to the same quality mammogram that I did. I continue to dedicate myself to making this the rule rather than the exception.



I am not overreacting

I do not remember how I physically left the clinic. How does one walk? What are on-lookers thinking or what do they say to you? What tone of voice do people use to say good-bye and step aside to let you leave, knowing you are so upset?

I remember closing the door of the clinic and finding myself facing the passers-by on the street, with tears on my cheeks. I stood on the sidewalk and the tears flowed freely. I did not care that people would see me. I called Gustavo and tried to calmly explain to him what was happening as I paced from side to side in front of the clinic. I asked him to act normally in front of my daughters.

I also told Leticia Rivera, our girls' art teacher, and I asked her not to say anything to Hannah about the mammogram because there was still no confirmation that there was a problem. I only hoped that Hannah, my intelligent and perceptive daughter, would not suspect something out of the ordinary had happened.

I did not want to frighten the girls. I myself was terrified enough.

I thought about how and when to tell Julio. My heart sank because I feared an indifferent reaction from him as a reflection of how I had often been overly worried about my health issues. At any rate, he was on his way back from a meeting in Geneva at the World Health Organization and I would not be able to speak to him until he reached his stopover in Madrid. I realized that was a good thing, because I could not talk to him until after I saw Dilys. I was sure I would be calmer and better informed after seeing her.

In the 15 or 20 minutes of travel between the clinic and Dilys' office, I calmed down a bit. I could not allow myself to become hysterical in the car. Indeed, there are times when one must act normally and calmly, even though everything inside and around you is chaos. Once again, I was learning to use everyday life as an anchor to control my emotions.

I finally arrived at Dilys' office. She was with another patient. The wait was longer than expected and those few minutes became hell for me. To stay calm, I walked from one side of the



waiting room to the other, but eventually this stopped helping. I began to feel that I was losing control of my emotions, so I quickly picked up some brochures to distract myself.

Unfortunately, I grabbed a brochure about cervical cancer that was on the receptionist's desk. Looking at the pictures, I realized that, despite having used the word cancer many times, despite being at my father's side when he died of stomach cancer, and despite accompanying my best friend Renata a few days before her death from thyroid cancer, I had never seen a photograph *of* cancer. I had never looked at a malignant tumor. The photos in the brochure changed that. I saw invaded tissue and I realized how the cancer grows and takes control of one's body, penetrating healthy organs. My eyes filled with tears and the repulsion rapidly converted itself into terror as I stared at the whitish tumor masses penetrating previously healthy tissue.

When Dilys opened the office door, she took me in her arms. "You have reason to cry," she said. I realized that even though we were friends, we had never embraced like that before. She is very tall and I reach the level of her shoulder. In fact, I fit under her armpit like a young bird in the wing of one that is fully grown.

I tried to unload everything I was feeling on her at that moment, but I could not cry because I was so terrified. The fear, almost like an anesthetic, had paralyzed me.

Dilys looked at the images and examined my breasts. She explained that the tissue where the tumor was thought to be located felt very hard, and what she was feeling was not present the year before. She gave me a different probability than the radiologist—"70 percent"—and pronounced the words with a look of outright concern.

Dilys was, and has always been, completely honest with me. She has been a pivotal source of support throughout my ordeal with cancer. Dilys never tried to make me believe that things were better than they were.

I asked for her opinion about what to say to Julio. She answered: "Tell him that I said that this time, for the first time since I have known you, you are not exaggerating; that this is not you



overreacting. You need to tell him that this is likely to be serious; that the image is very suspicious.” This was one of the moments – and there would be many more to come– when time stopped. It was the moment I realized that I truly had, not a serious problem, but a very serious one.

We began to discuss the next steps, to plan what to do and with whom. I was anxious to resolve everything about where to go for treatment, what doctor to talk to, and when to do so. The first issue was where to go for the biopsy and who would perform it. Although I did not understand this at the time, eventually I would have to decide how and where the surgery would take place and with which surgeon, who might also be the person who did the biopsy. I remember this as the first ‘decision-making moment’. I had no idea that it was the first of many that I would face, each one more difficult and anxiety-provoking than the last.

Months later, when I began to read the testimonies of other women who lived through breast cancer,¹⁰ I realized that my experience and anxiety with decision-making were not unique. Cancer brings with it a tangled storm of decision-making that generates a chain of perpetual anguish.

Dilys and I talked about medical insurance. I was not sure I was completely covered and that created a new source of distress: how to finance what was coming. Several days later, I found out that I had the tremendous good fortune –thanks to my husband’s work and a wise and generous decision of a friend at the Bill & Melinda Gates Foundation– to have medical insurance that covered me in Mexico as well as in the United States.

In hindsight, I am aware of how very important it was for me to experience this moment of additional anguish related to the financial aspects of my treatment. It made me understand, if only for a few days, what millions of people diagnosed with a significant health problem suffer when they lack financial protection for their health care.

¹⁰ Shapiro M. *Life in the Balance: My Journey with Breast Cancer*. Toronto: Harper Collins Publishers, 2006; and Marchetto MA. *Cancer Vixen: A True Story*. New York: Alfred A. Knopf, 2006.



Until that moment, my almost two decades of work on health financing in developing countries and in support of the development of *Seguro Popular*¹¹ in Mexico had been an analytical, arm's length experience.¹² My work had been done from the desk of a health economist and as a policy advisor. It was always from the comfortable position of tackling a problem –the lack of financial protection in health faced by billions of people around the world– that had never affected me directly. The distress of being unable to afford health care or having to deprive your family of things they need in order to be able to pay for your health, only comes to life when you experience it in the flesh, as a patient.

It is not the same to learn about a health system as it is to live in one. Some three years later, Julio summarized his experience as a caregiver accompanying me through the disease, compared to his time as Minister of Health of Mexico: “It is not the same to live as to lead a health system.” A few weeks after my diagnosis, this awareness would be transformed into a source of inspiration to develop a program that eventually led to the birth of a civil society organization, a global task force, and a line of research.

Dilys and I decided to first call my sister-in-law, Alicia, a doctor of great prestige in Mexico who would become another pivotal source of support in facing my health dilemmas. After dialing a few times, I managed to get through to Alicia but I quickly passed the phone to Dilys so she could explain the situation. She shared what information we had and impressed upon Alicia the apparent

11. *Seguro Popular* was created through a major reform of the Mexican health system, undertaken in 2004 when my husband was Minister of Health, to provide financial protection for health care to all Mexicans who lacked access to social security. In 2012, the country achieved universal health coverage. Knaul FM, González Pier E, Gómez Dantes O, et al. The quest for universal health coverage: achieving social protection for all in Mexico. *The Lancet* 2012; 380(9849): 1259-1279.

12. Knaul FM, Arreola-Ornelas H, Méndez-Carniado O, et al. Evidence is good for your health system: policy reform to remedy catastrophic and impoverishing health spending in Mexico. *The Lancet* 2006; 368(9549): 1828-1841; Frenk J, González-Pier E, Gómez-Dántes O, Lezana MA & Knaul FM. Comprehensive reform to improve health system performance in Mexico. *The Lancet* 2006; 368(9546):1524-1534; Knaul F & Frenk J. Health Insurance in Mexico: Achieving Universal Coverage Through Structural Reform. *Health Affairs* 2005; 2: 1467-76; Seguro Popular de Salud. <http://www.salud.gob.mx/unidades/dgpfs/jaq.htm>.



severity of my case. These two women –doctors, confidants, dear friends, and, in the case of Alicia, family– then discussed my body and my health in ways that made me tremble and at the same time feel some security and comfort. They began to work through what would be a very long process of next steps to take, beginning with the selection of a surgeon and the biopsy.

I desperately wanted to convince myself that this was not happening to me; that Dilys was speaking to Alicia about someone else; that they could not be talking about me. But the constant shadow of catastrophe was already, and at the time I thought permanently and irreparably, looming over my life. I was beginning to internalize how this phantom would accompany me for a very long time. Moreover, I started to again notice that everything was happening as if reality was taking place outside of me. Felicia, the person they were discussing in such great detail, was merely a spectator to the show. It was not a comfortable feeling, but I found it equally uncomfortable, if not more so, to be ‘present in the present’.

By the time it was my turn to speak to Alicia, I was very agitated. She had to be tough to contain me, which I remember angered me at the time, but for which I am now very grateful. Quickly and confidently, she proposed a surgeon, Rubén Cortés, who operates at the Médica Sur Hospital¹³ and in the *Instituto Nacional de Ciencias Médicas y Nutrición Salvador Subirán* (National Institute of Medical Sciences and Nutrition),¹⁴ where Alicia heads the outpatient department.

Alicia reminded me that Rubén had operated on me two years prior when a lump appeared on my neck. That lump turned out to be nothing more than an infection and, of course, an over-reaction on my part. At that moment, I remembered how afraid I had been of that little lump in my neck, which ended up being benign. The memory of the neck operation did not help, because I thought to myself, with a worrisome mixture of certainty and uncertainty, that this time, the little ball was of a different magnitude and another type.

¹³ See: <http://www.medicasur.com.mx>.

¹⁴ See: <http://www.innsz.mx/opencms/index.html>.



I changed the tone of the conversation by consulting Alicia about one of my major concerns of the morning, a concern that to others might have seemed trivial: our long-dreamed-of vacation to Disneyland. Julio and I had put so much time and effort into planning the trip for our two daughters, Hannah and Mariana.¹⁵ Maha was three and would be going for the first time. Our departure date was in four days. Alicia immediately took up the battle of convincing me not to forfeit that opportunity, because nothing would change in a week. This conversation would continue for days and keep us both busily thinking about something other than the future of my health.

After speaking with Alicia, Dilys and I decided to look for Misael Uribe, who had been my gastroenterologist for many years and also the president of *Hospital Médica Sur*. Misael gave me the same recommendation as Alicia: Rubén Cortés. He also offered to try to contact Rubén so that I could see him as soon as possible – on Monday. I remember thinking: “Monday is the day after tomorrow and I cannot possibly be ready for surgery the day after tomorrow because I have so many other things to do...” Yet at the same time, and in stark juxtaposition, I was tortured by facing what seemed an eternity: to wait 48 hours for more information and clarity about my situation.

Tell me I *am* overreacting!

Finally, back in the car, heading home, sad and more exhausted than distressed, I was able to reach Julio. He had just arrived in Madrid and was awaiting his flight back to Mexico. As soon as I heard his voice on the phone, I realized that I would have preferred that he had not answered my call. For a brief second, I had the inkling to just hang up and pretend to us both that nothing was

¹⁵ Mariana Havivah is Maha for me. First because a Maha is a beautiful woman in Spanish; and second, because my pronunciation in Spanish of Mariana is embarrassing to us both.



wrong. I kept thinking that he would dismiss what I was going to tell him as unimportant.

I repeated Dilys' exact words: "Dilys asked me to tell you that this time I am not exaggerating." And I went on: "Julio... I think I have a serious problem..." I proceeded to try to explain everything that had happened in barely three hours: the mammogram, the ultrasound, and the conversation with Dilys.

Looking back over the months and years of my life with cancer, I realize how fortunate I am to have Julio as my partner. The only rejection that I ever had to fear from him was denial of the initial diagnosis. In an interview for *Science*,¹⁶ more than three years after my diagnosis, a reporter asked me about this precise point – had I ever felt rejected by my partner, by Julio. I thought through all the months and years of life with the disease and answered him with conviction, "Never." I also realized and shared that I was unsure if I could have done for Julio what he has done for me. To be a caregiver for a person with cancer takes strength of character and commitment that I hope are never tested. I pray that our roles are never reversed.

I highlight the importance of Julio's commitment because it is strikingly different from what so many other women with breast cancer experience from their partners. In fact, it was Julio who insightfully wrote that stigma, discrimination and machismo are the social cancers that prevent women from seeking health care and diagnosing breast cancer early enough to make treatment effective.¹⁷

I recall that when I shared the news with Julio for the first time, I wanted him to dismiss my fears and tell me that I was wasting his time. I wanted to hear that the mammography results were not important and that I was, once again, overreacting. This time I really wanted it to be different – I was still hoping that I *was* overreacting.

¹⁶ Enserink M. A push to fight cancer in the developing world. *Science* 2011; 331(6024): 1548-1550.

¹⁷ Frenk J. Awareness, early detection, and combating prejudices: Keys to fighting breast cancer. *Salud Pública de México* 2009; 51 (Suppl.2).



By that time, it was almost two in the afternoon. Julio reserved his judgment about the gravity of the situation. We agreed that the next step would be for him to talk to Dilys, and I gave him her phone number.

I waited in the car. Julio called me back almost immediately and said in a calm tone of voice that I found hard to believe because he reduced the probability of malignancy from what Dilys had told me: “Dilys told me 50 percent.”

A long conversation ensued, between Madrid and Cuernavaca, about what to do next. This was much more worrying. Julio hates to talk on the phone. Yet, this time he was not using his typical voice of total frustration (which angers me so much), the voice he reserves for when I keep him on the phone, especially on an expensive international call.

I remember that I stayed in the car, parked outside the house, to talk to my husband. I continued the conversation there because I did not want the girls to find out what was going on. In fact, I remember exactly where and how I was seated during that telephone conversation; again as if it were a movie and I was a spectator rather than the main character.

We came to the topic of our trip to Disneyland, and Julio said that we were obviously going to cancel. I remember how vehemently I answered him: “Absolutely not!” In that instant I began to sob, and gave him the best and most hard-hitting reason for not cancelling, truly a reason so powerful that it scared me to say it to him: “Julio, it may be the last time that I can take my daughters on vacation.” I remember that at first he did not answer. There was a brief silence. Then he said to me, with affection in his voice, that I should please not worry about the trip. That we would go to Disneyland.

Julio also said that he was going to start making phone calls to physicians and friends. This was the confirmation of what I already knew to be true: things were bad, perhaps very bad.

Julio spent the next four hours on the phone while he awaited the flight that would bring him to Mexico the next morning. He spoke to Alicia and to Misael, and they were both trying to



contact Rubén, who was turning into a focal point for me. I, in the meantime, was in our house awaiting Ruben's call and at the same time, fearing the moment I would hear his voice.

Julio telephoned me repeatedly to give me news. I remember that he spoke to me very affectionately and that I would still have preferred to hear the typical note of frustration for unnecessary international calling from Europe. It was another sign that things were looking bad for me.

It was not until eight months later that Julio shared his memory of those disturbing hours in the Madrid airport. We were on our way back from a vacation in Europe to celebrate the end of 16 rounds of chemotherapy and we stopped at the same lounge. He showed me the table and the chair where he had sat for hours, with his own level of anxiety ever increasing, making phone calls to try to ensure and organize the medical care he was certain we would need.

Next steps; first decision

After ending the first round of calls with Julio, I remained seated in the car in front of the house. It was clear to me that I could not go inside to greet the girls with the fear and panic that were eating me up inside and were surely reflected in my face. I am basically a rational woman, and at that moment I needed to preserve that feature of my character in order to calm myself and protect my daughters.

I was exhausted. My mental and emotional stability had been disrupted in a matter of hours. I had a wealth of questions and a dearth of information. Yet, I tried to set those thoughts aside in order to determine how to initiate a process that I did not know how to begin. What I remember most are the repeated and combined sensations of terror and doubt, fueled by the lack of information and clarity around my situation.



Somehow, and for the first time, I realized that my greatest fear was of the chemotherapy, but I had no inkling as to why. Sitting in the car I kept thinking and saying over and over to myself, “I would rather die than go through chemotherapy.” The fear just hovered around me, mixed and muted with the uncertainty of a partial diagnosis. I could not yet fathom how both the Nazi concentration camps¹⁸ and my father’s experience were bound up with my own fear of cancer and chemotherapy.

I do not know how long I sat in the car, waiting to calm down before going into the house. I also cannot remember how I got out of the car, because I know I was shaking and my legs were jelly-like. What I do recall is watching myself, once again like a spectator, walking along the garden path and up the steps towards our dining table. Reality hit when my little one, Maha, came running towards me to give me one of her full-body leg-hugs.

Next I saw Hannah, then 11 years old. She nonchalantly said that Leti had told her everything. Fortunately, the only thing I thought of asking her was, “What is *everything*?” She explained that she knew I had had problems with my medical exam. I realized, from the matter-of-factness with which she was speaking, that she either had not grasped the seriousness of the situation or did not yet want to understand it. Either way, Hannah was making use of a wonderful tool that tends to be highly developed in children: to take in no more than what they can and need to assimilate.

At that moment, I made my first truly important decision, one that determined many that would follow. I suddenly remembered with absolute clarity my own anger and terror when I realized that my father’s cancer was much more advanced than what his doctors had led us to believe. With this memory in mind, I decided

¹⁸. For more information on Nazi concentration camps and the Holocaust, the mass murder of six million Jews by the Nazis during World War II, see: Museum of Jewish Heritage, A living memorial to the Holocaust, <http://www.mjhnyc.org/findex.html#.UGLdsmgW34c>; Yad Vashem <http://www1.yadvashem.org/yv/en/holocaust/about/index.asp>; Gutman I, editor-in-chief. *Encyclopedia of the Holocaust*. New York: Macmillan, 1990. 4 volumes; Rozett R & Spector S. *Encyclopedia of the Holocaust*. Jerusalem: Yad Vashem with Facts On File in the United States, 2000. Available at: <http://secure.yadvashem.org/store/product.asp?productid=319>.



that, come what may, I would seek to protect my daughters from fear, anguish, and anxiety, but not from the truth. I had to be honest and open with them, as I had asked the physicians and my parents to be with me when my father became ill. I knew with a strong sense of certainty and clarity –in contrast with all else that I had experienced that day– that I had to always tell my daughters the truth, but that I only had to go as far as they needed to hear and no further. Hannah and Maha would not become the receptacles for my anguish. On the contrary, I had to find the courage to deposit in them confidence, security, and affection, and not my fear. These first decisions, focused on my daughters, were a great source of strength.

I armed myself with the only guide I had at my disposal that afternoon: my experience with my father’s cancer. That experience –lessons from myself at age 17– served me well.

I decided that the first thing I should do was to simply listen to Hannah. I recall that she said little, but that what she did say was expressed emphatically and provided me with essential information. Hannah taught me how important it is to listen to children in order to know what they can tolerate and what they need to hear. Fortunately, children, if you listen to them, tend to let you know exactly how much information they can process. When they get to the point of overflow, they usually stop paying attention. This, I have to acknowledge, is a great coping strategy.

Hannah responded with some frustration to my repeated questioning. “I told you, Mom, I already know everything. You had an examination that didn’t turn out very well, and maybe they have to do more things to you, and that I have to give you a hug.” I replied by receiving and returning her embrace, accompanied by the only concrete information that I had at that moment: “We still don’t know anything... Dilys is taking care of me. She is a great doctor. And, yes...yes, we will go to Disneyland next week... Now, the three of us are going to have some lunch – you, your sister, and I, together.”



CHAPTER 2

Pause to enjoy the world of the healthy

The wait

I could do nothing in the two days that followed. Just wait and try to distract and anesthetize myself by carrying on with my life and my work. Every moment was painful. I cried easily and regularly. Any attempt to undertake life normally was uncomfortable. I tried to make time pass as quickly as possible while awaiting news. Yet I simultaneously dreaded the passage of time, fearing that I might not have much of it left.

I learned that the time between the emergence of suspicion and the diagnosis of cancer is a painful pause. One is frozen in time and inside a body that may be ill, infiltrated by a potentially fatal disease. Both you and your life are on hold. Mind and soul must become dormant in an attempt to manage the specter of uncertainty, and simply allow the precious yet painful moments to go by.

Years later, I met up with a former student who was then facing breast cancer. She was awaiting her complete diagnosis and treatment recommendation. With only partial information, she was bereft of knowing even what her immediate future would bring. She awaited news that she desperately needed yet did not want to hear. At first, I tried to brighten her spirits, to bring her back to life. In hindsight, I recognize that just as I had done at the same point in my journey with cancer, she had anesthetized herself. This was a good coping strategy, although it created a barrier that prevented me from reaching out to her more directly. She was living the painful pause just as I had done.



Speaking with her made me realize how I had lived through those first days of uncomfortable ignorance. I understood nothing of what the future might bring or what lay ahead and a part of me longed for knowledge. Only time, information, and experience would take away the feeling of catastrophe and terror that shadowed me constantly.

I chose to anesthetize myself with work. Gustavo and I rescheduled our work meeting for that Saturday afternoon. As a good friend, he was upset and worried. I convinced him that working would help me to cope. It distracts you from thinking about being ill, and during the months that followed, I would resort to this mechanism time and time again.

I also remember talking to Sonia Ortega, one of my closest colleagues. She would be at my side for the entire ordeal, throughout the many difficult months that followed. Her initial reaction to my news, however, was denial. She simply said, “It cannot be.”

We have very good friends who live near us in Cuernavaca, Rosa María López Lugo and Rafael Domínguez Morfín. They are among the few people in whom I place my absolute trust, in both personal and professional matters. Hannah and their daughter, Regina, of whom I am very fond, are close friends. I decided to call Rosa María and Rafael that afternoon and get the girls together to soothe some of Hannah’s worries, and some of my own.

“In difficult times, you must be with the family, and especially your children. Put your computer aside and come over with the girls to a Halloween celebration,” my friend Rafael insisted, after I shared what little I understood of the ordeal that had transpired only that very morning. What he was really saying to me was: “Celebrate life now,” and implicitly, “Because, sick or healthy, you never know how long the celebration will last.”

Rafael managed to convince me and he was absolutely right. Strange as it might seem, that evening the three of us went to a Halloween party. It did do me a lot of good to be out with Hannah and Maha and to spend time with friends. Still, I could not manage to shake off the enveloping cloud of anxiety that was smothering me.



To protect me, Rafael gave me a small image of a saint with a tiny piece of the holy man's clothing. I wore it over my left breast tucked against my skin until I got my diagnosis. This may seem somewhat unusual, especially because I am Jewish. But I am a Jew who prides herself on being open to different forms of prayer and to all avenues for reaching God. What was important to me about that holy image was that it came from my friend. At that moment, all and any help was welcome.

When the diagnosis finally came –ten days later– I decided not to wear the image on my chest anymore. This decision, in fact, had little to do with the diagnosis because I still believed in the power of friendship imbued in that holy image; rather it was because I would no longer be able to wear anything against my breast. I still have the image of that saint, and I carried it with me in my purse for years.

It may surprise some readers that I have not said anything about religion or God up to this point. I am a strong believer in God and a practicing Reform Jew. Before the specter of the cancer diagnosis presented itself, I prayed often and maintained a very personal line of communication with my God. It surprised, unnerved, saddened, and distressed me, but after the diagnosis, my ability to pray had vanished. At this time in my life when I most needed and wanted to pray, absolutely nothing would come out of my soul.

I analyze my journey back to prayer in depth in the last part of this book. It is enough, for now, to assure the reader that my inability to pray was not due to anger with the possible diagnosis of cancer – a valid hypothesis that many would put forward. Rather, my line of communication had been damaged. I could not trace and recover my path to God. This absence of prayer generated significant worry in me; I lamented the loss. But I was devoid at that moment of any way to even begin to approach the issue. What I did know was that there was now something hollow where before there had been a fullness of soul. Sometimes I wonder if I was preparing myself for other losses that I feared would come.



Julio finally arrived home early Sunday morning from Europe. He hugged me and I tried to pretend that everything was fine. I pretended for him as well as for myself. I realized as I tried to be strong for Julio that, for the first time in a very long while, we were functioning as a team. Still, I was terribly sad and sorry that illness was the cause. Unfortunately, though we were navigating together, the waters were treacherous and had neither compass nor oars.

I urgently wanted to talk to Julio about my mother. After a lengthy discussion with Alicia the previous day, I had *almost* decided not to tell my mother what was going on. Still, I was uncomfortable with the idea and wanted Julio's opinion.

I come from a small family. Since my father died in 1984, the Knaul-Windish family consists of just my mother, my younger brother, and me. The decision was painful. I knew she would be hurt when she eventually found out that I had hidden the truth from her. But she had undergone a knee replacement just six weeks earlier and was still recovering. Alicia wisely convinced me that it was better not to give her the news of my mammogram over the phone, especially because we still did not know anything for certain.

My mother was flying from Toronto a few days later to visit us in Mexico. She was to arrive on November 8 to celebrate her eighty-fourth birthday with us. By then, Alicia assured me, we would have a lot more information and something concrete to tell her.

I consulted with Julio and he agreed. He said that the news and uncertainty of a suspicious mammogram would be very hard for her to cope with – especially alone and far away. I was torn, but I agreed.

I still think I did the right thing. And I hope my mother has finally forgiven me.

I did write to my brother Jonathan, who serves as a pilot in the Royal Canadian Air Force and was in Europe taking a course at the time. I remember how painful it was to tell my 39-year-old 'little brother' that I might have cancer.

Most of Sunday was spent talking with Julio about the possible meaning of the mammogram. In hindsight, I do not think we



ever used the word ‘cancer’. Ironically, we spent a lot of time talking about the trip to Disneyland and whether it was better to cancel it or not.

I had not yet been able to speak to Dr. Rubén Cortés – the surgical oncologist whom I needed to see. I recall how that word ‘oncologist’ made me cringe with fear. Only one and half days would pass before I would ‘finally’ be able to speak with him, but the wait was sheer agony.

I now realize how short my anguished wait actually was in comparison to even the most privileged of patients; how unusual it is that I was able, and still am, to access my physicians by phone or email almost any day of the week. Months later I was made to understand that many cancer patients in both low- and high-income countries often wait much, much longer –maybe weeks, maybe months– to speak to an oncologist. My own fortune, my incredible access to physicians who have become my friends and colleagues, indeed inspired much of the work that I would soon take on in response to the challenge of breast cancer.

Finally, late on Sunday night, my long-time gastroenterologist Misael Uribe, who had seconded Alicia’s recommendation of Dr. Cortés, was able to reach him on his cell phone and ask him to contact me. When my phone rang, we were in the car on our way back to Mexico City. Julio was driving, and Hannah and Maha were mercifully asleep in the back seat. I explained what I could about the BI-RADS and the mammogram and asked for an appointment the next day. My heart sank when Dr. Cortés said he was leaving for a medical congress very early the next morning, and that he would not be back until Thursday, the day we were supposed to leave for Disneyland.

I asked if he could please speak with Alicia and Dilys, and in the first of many acts of kindness and generosity, he agreed. When he called me back it was about half an hour later, though it had felt like an eternity. Rubén assured me that whatever the suspicious image on the mammogram was, there was no immediate urgency and I could wait to see him until I got back from Disneyland or until he returned on Thursday or Friday. He also offered to recommend another doctor if I was too anxious to wait.



When the call was over, a feeling of desperation swept over me and I became extremely anxious. I either had to wait days for a diagnosis or look for another surgeon. I started torturing myself with useless thoughts of what could have been: “If you had only been able to reach him on Sunday afternoon, you could have seen him today; you would know.” The *‘if only’s’* made me even more confused and anxious.

In retrospect, however, the delay was wonderful.

Disneyland... To go or not to go

Coping with the period of time between detection and diagnosis –which for many turns into weeks or even months– is torture.¹ It is as though you are suspended over the edge of a cliff, but without ever having jumped – hanging in the air, looking down into the depths. You do not know if you are destined to fall in or if you will still be safely walking along the edge only a short while later. These uncomfortable moments of suspense are the result of not knowing what, if anything, is wrong with you, or what you will have to face if indeed you have the disease. You cannot judge the depth of the hole you are teetering over.

I still did not know if what I had inside me was cancer or not. And as I tried to navigate the somber news and the uncertainty, I could see a pinhole of happiness: the chance to be with my girls on a vacation they so much wanted. I recognized that this was an opportunity, a beacon of light in a period of darkness that could last a very long time.

1. Having read several testimonies, I realize how difficult this wait after a mammography is for all women. The following books provide especially poignant accounts: Shapiro M. *Life in the Balance: My Journey with Breast Cancer*. Toronto: Harper Collins Publishers, 2006; Balwanz P, Carlos K, Johnson J, Peters J. *Nordie’s at Noon: The Personal Stories of Four Women “Too Young” for Breast Cancer*. Philadelphia: Da Capo Press, 2007; Lucas G. *Why I Wore Lipstick to my Mastectomy*. New York: St. Martin’s Griffin, 2004; and, Gralow JR, Susan G. Komen Breast Cancer Foundation. *Finding your Way to Wellness: Puget Sound Breast Cancer Information and Resource Guide*. Seattle: Susan G. Komen for the Cure, 2007.



I now realize that I diverted all my anxiety over the uncertainty of my health into deciding whether ‘to go or not to go’ to Disneyland. I pretended to myself that, amidst all that was happening, making the trip was really a momentous decision. I spent hours, many hours, going over options for the Disneyland trip, trying to find an option that was compatible with getting an earlier diagnosis.

I went to see Alicia at her office in the hospital where she works. Under my arm, I carried the huge manila envelope containing my mammogram and the ultrasound images. The envelope seemed larger than me. I was determined to ask if the radiologist at Alicia’s hospital could give me a second opinion. I convinced myself that this would help me to make a more informed decision about waiting a week to see Rubén.

It was Monday, October 29, around ten in the morning. I dumped the huge manila envelope with the mammography results on her office desk and sat there staring at Alicia while she, in turn, stared at the images of my breast. I searched for any detectable expression on her face, any gesture or reaction that might provide me with an indication of her opinion as to what was living and growing inside of me.

Alicia left her office with the images –the envelope seemed smaller and more manageable under her experienced arm– and came back about 15 minutes later. She said that she had reviewed the images with one of the best radiologists in Mexico and that in his opinion, it might be a BI-RADS 4, but maybe an ‘A’ instead of a ‘B’.

The reader should know that in the case of BI-RAD scores, higher is worse – 4 is worse than 3, and B means a higher suspicion of malignancy than A. I was still ignorant of these nuances and it did not sound like particularly good news to be an A as opposed to a B player. Alicia shared this news –the best she could muster– with me: Her radiologist thought there was a slightly lower probability of the lesion being malignant – slightly less than the 60-70 percent that the radiologist in Cuernavaca had indicated.

I asked Alicia to examine me – a plea more than a request.



I was self-conscious; I had never taken my clothes off in front of my sister-in-law. It was a clear indication of my desperation, but also of my firm belief in her capacity to give me medical and non-medical advice in all aspects of my life. I wanted to let her make a decision that I myself could not make. I was an adult trying to act like a child and searching for a way out of taking responsibility for my own decisions. I wanted Alicia to provide a platform of security above the abyss of uncertainty over which I was teetering.

While she examined me, I scrutinized her face. I was looking for any change in her eyes or her expression. Anything that could make me feel more relieved or perhaps more worried, but would at least free me of the uncertainty. Nothing. Alicia delicately probed and kneaded my left breast without demonstrating any reaction. Thinking back, I remember that she turned her head away while she examined me, but at the time I wanted to believe that she was just concentrating on her task.

It was years later that I realized that she was trying to hide from my gaze and from my insistent questions. If Alicia had told me at that moment, as she later did, that to her touch the tissue “felt hard, horrible and ugly,” I would not have gone on vacation with the girls.

She helped me to make a decision that I would not have been able to make if I had had more information: the decision to take a pause in the midst of my cancer diagnosis and enjoy some time with my family.

Alicia, of her own volition, is a concrete retaining wall that withstands a huge burden of emotional weight heaped on by family, friends and patients. I was, and still am no exception. Throughout the entire week that followed, she absorbed all the pressure of what was going to happen to me, and allowed me to live for a few days as if I were not facing a cancer diagnosis. She insisted on the value of postponing the biopsy for that one week.

Alicia knew what I did not: that those few days would not change medically what I and our family, including her, would later face. On the other hand, the vacation would strengthen us emotionally and produce good memories that would cushion the difficult times ahead.



I continued to invest huge amounts of time over the next three days stressing out, trying to decide which to postpone: the trip to Disneyland or the biopsy. There was no way for me to comprehend at that stage that my situation was not an emergency. In fact, it took me months to understand and accept that successful breast cancer treatment is a long, complex, and drawn-out process with mercifully few emergencies along the way.

Alicia and I discussed the possibility of contacting other surgeons. She offered to look for another doctor for me, but at the same time she insisted that she would rather Rubén be my surgeon and that we go away with the girls until he came back to the city. She reminded me that Julio and I did not usually set aside vacation time and that we should not miss out on what we had already planned.

Then, after taking great pains to convince me, she allowed me to continue to argue with myself about what to do. Seated together in her office on a busy Monday, with needy patients waiting, we conducted a ridiculous review of the days ahead. If I did not go to Disneyland, and instead went to see Rubén on Thursday, and got the biopsy that day or on Friday, we would not gain anything, because I would still have to wait all through the long holiday weekend for the results. Moreover, we reasoned that if I changed the flights and returned just one day earlier, on Sunday, I could go to Disneyland, see Rubén on Monday and have practically the same waiting time. We were debating about nothing, but she was trying to help me rationalize, and was guiding me towards a decision.

That day was also a Monday, and like all Mondays, as if it were just any Monday, there was work to do in my office at the Mexican Health Foundation. So after the visit with my sister-in-law, I went to my office. Close colleagues had been advised of my health situation on Saturday. I could read in their faces the worst case scenario that my mind was conjuring up and striving to avoid. Sonia was still in denial and attempted to make everything seem as normal as possible – she sensed the hell that I was going through.

Talking to Héctor Arreola was especially difficult for me. For him, facing me was worse. His wife, Loren –a doctor– had died



at the age of 34 from breast cancer, just a year before, in July of 2006. She had left Héctor, also in his early thirties, widowed and the father of a five-year-old girl born just a few months before Loren detected her own cancer.

My friendship with Héctor goes back to 1997. He was one of my first students and soon became one of my closest collaborators. He faced my likely diagnosis with compassion, friendship and discretion. Héctor stayed close to me, but never spoke about what we both feared. We both knew that he had lived what could happen to me. Despite my impatience for information, I never asked him any questions. I was simply too afraid of the possible answers. Yet, the closeness that came to be in those anxious days has endured and our friendship has deepened. I think that we have learned how to grieve together.

I entered my office and took my place at my desk. I felt strangely uncomfortable with everything around me. In an attempt to maintain my composure, I gazed at the books I had collected over the years, and at the drawings and paintings that had been made by Hannah as a child that decorated the walls: everything seemed to radiate a strange, pulsing light. Even the little blue ceramic fountain that sat on my desk, and the trickling sound of the water running over the pebbles that I normally enjoyed, made me tense. In retrospect, I know why: How could I enjoy the present when I feared I might not have much time to appreciate all I had? I finally managed to calm myself down, yet doubts slithered continually into my thoughts. I could not stop myself from imagining the worst over and over again, and becoming, with each round, more afraid.

I forced myself to recognize that I had to organize the professional side of my life. This calmed me down as it helped me to stop thinking about the possible diagnosis.

I had several projects due in November and December. I knew that if the lesion turned out to be malignant I would not be able to work as I normally did – at least for a while. I took refuge in the pressures of work, and convinced myself that until I had a confirmed diagnosis, I would put aside uncertainty –as best I could– and make good use of my time.



I had a meeting with my closest collaborators – Héctor, Sonia, Sonia Peña, Gustavo, and Julio Rosado. We decided to make a herculean effort to finish a particular project that same week, and to make serious inroads into another.

During the three days of intensive work that followed, there were many times when I had that same strange sensation that I had lived during the first mammogram – moments in which it seemed like I was no longer present and was watching myself go through daily life as if I were on a stage. I could see myself as if I were looking down from outside my own body. I could hear my own voice as if I existed outside of myself. I was an external inhabitant of Felicia, while still being Felicia.

The serpent of uncertainty weighed on me as if I were carrying it tied around my neck. My hands would grow cold repeatedly. When I could no longer stand it, I would busy myself by turning to the familiar decision of whether or not to go to Disneyland.

Although I knew I was driving everyone crazy –especially my husband, and my friend and travel agent, Marcela Lozano– I took full advantage of the indecision to offload my tension. I channeled it all into Disneyland. This was the true value of continuing to postpone the decision about the vacation: it distracted me from thinking about the biopsy.

Alicia would call me every two or three hours to reflect on the cataclysmic, and retrospectively ridiculous, Disney decision. She always had the same advice: “You should take the vacation.”

To be honest, Alicia and I tend to have these sorts of conversations over less traumatic, but similarly difficult decisions. We are both experts in going back-and-forth over any trip, always worrying about who will stay behind. Family events are endless planning experiences. Any phone conversation can last and last, while we both go around our respective houses taking care of all the things we did not get done during the day. In Spanish –which is the language we always use to communicate with each other– we joke that we are doing *güiri-güiri*: the sort of bantering conversation that helps each of us arrive at a decision that we should have been able to make much more easily.



I had convinced myself of a ridiculous strategy that could only help to save me at most 24 hours of uncertainty: I would wait until Thursday when Rubén would review the images. If he agreed that they seemed worrisome (I ask myself today, “Was there really ever any doubt that he would?”), then I would return alone Sunday night to see him first thing Monday morning. This would move *everything* up by one day (although, of course, I had no idea what *everything* was and even less an understanding of what a biopsy entails).

This torturous indecision-making process continued to be useful for displacing the uncertainty about the suspicious mammogram – and for mentally and emotionally exhausting me by obsessing about something that had nothing to do with my physical health.

Finally, I decided to change nothing and to take the trip to Disney just as we had originally planned. I was still part of the world of the healthy, even if it was only for a little while longer.

Though it sounds childish: The magic of Disney

The trip to Disneyland was a gift. I acted as if I had not had the mammogram and as if there were no doubt about my health. And although at first I was tempted, I did not call Rubén, or Dilys, or Alicia to ask useless questions.

I had to exercise incredible control over my emotions and my thoughts. Sometimes they got the better of me and I drifted off into never-never land; but I managed to control them – most of the time. From Thursday to Monday, I was aware, deep down, that I had to go back to finish living out the nightmare. But in the meantime, I afforded myself the luxury of letting time pass and simply having fun.

I dared to play. I became a little girl with my girls. I did things that I had not done in decades. Maha and I went on the carousel many times, together on one horse. I spent my money on things



that I would have considered frivolous, if not ridiculous, before. In the princesses' beauty parlor, I painted my face like a butterfly, the same color and style as Maha, and we walked through the park like that all day. I allowed Hannah not only to paint her face but also to do her hair like a princess – which was more costly than most Paris salons. We had a blast!

My personal favorite was the Tiki Room, where I sang along with the flowers and the animated birds, embarrassing the whole family, except me. I liked it so much that I made everyone go a second time the next day. Somehow Julio convinced me that the third round of *Tiki-Tiki-Tiki*² was too much and I pouted for an hour. Finally, to make myself feel better, I snuck away and bought Maha a Princess Jasmine outfit, complete with purse and shoes.

During those four days, Julio and I hardly spoke of the cancer or what would happen the following week. We devoted ourselves to Hannah and Maha. We lived through them. We spent all day having fun, from morning until late at night. We would get to the hotel, which we also enjoyed, exhausted but ready for the next day of fun.

On this trip, I began to change my way of living. I started to grasp the true meaning of 'wasting time'. I began to fall in love with life, with everything that produces a smile, and with anything that is capable of bringing color and music into the spaces in which we live.

This change came about not so much because we were in Disneyland, but rather because I saw my daughters happy and enjoying themselves. The hope of being able to repeat this on another occasion would be of great help, when, only weeks later, I was trying to face up to the chemotherapy.

Re-encountering prayer, at least temporarily, was also a relief. I was able to thank God, with ancient Hebrew words, for having given me the opportunity to live those moments, for sustaining me, and for having guided me to that point in my life. Indeed, for giving me life. I prayed not with gratitude for what had happened,

². Disneyland Enchanted Tiki Room. <http://www.youtube.com/watch?v=fhApjPASb64>.



but for what was happening – the moments I realized I was enjoying. I never asked God for anything. I never asked for health. I simply felt thankful, and that was my only message to God. I was still concerned about why I was unable to pray more or ask for more, but I was learning to accept it.

I realized that, like a small child, I was just beginning to appreciate my surroundings. It was very strange, as if my senses had been dulled all my life. I was still not entirely conscious of what was happening to me. I simply realized that I was determined to enjoy as much as I could these moments while I still felt totally healthy; determined to live the hours as a person who is not sick, without worrying about the mutilator that I knew had invaded my body, but which, at that exact moment, had no power or importance. The capacity to focus on the beauty around me would in fact increase as I moved into the cancer treatment.

Lesson learned: enjoy each and every moment to the fullest and live in the present.