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Living your Fullest Life after Breast Cancer

Felicia Knaul and Maja Pleic

As women age, we have many changes to look forward to as the uncertainties of love and employment blossom into the stability of family and career, and the anxieties of youth are transformed into the wisdom of maturity. Upon my 40th birthday, I had much to be grateful for: two beautiful and kind-hearted daughters whom I adored with all my heart, a loving husband and partner in life, and my labours of twenty years in health and development economics had solidified my career as an expert on health systems in Latin America. There are also other, less favourable changes associated with ageing such as the increased risk of many noncommunicable diseases, including breast cancer. My gynecologist and dear friend advised me that as I entered into this new season of my life, it was time to include a mammogram in my annual health check-up. I was extremely nervous for my first mammogram, and despite having worked in women's health for years and knowing full well that screening is the best way to protect oneself against breast cancer, I must admit that I delayed mine for months.

I now know that my anxiety is shared by millions of women all over the world who step into a doctor's office for a mammogram, brimming with fear and worry — for their families, their health, and their lives. Even worse is the case of those women whose fear keeps them from getting a mammogram, or who do not have access to one at all. Indeed, my work in global cancer

care and control has taught me that fear, stigma and lack of access to care fuel global breast cancer mortality.¹

On the one hand, the overwhelming fear I felt is certainly understandable. Breast cancer is the most common cancer among women worldwide, and the second most common cancer in the world overall.² It is the number one cause of cancer deaths in women in less developed countries, and the number two cause of cancer deaths in women in developed countries.²

On the other hand, if it is caught before the cancer begins to spread, and with access to appropriate treatment, nine out of ten women can expect to live at least another five years, and many live much longer.³ For this reason, regular screening is the best strategy we have in the fight against breast cancer. For me personally, facing my fears and going in for my first mammogram saved my life and allowed me to enjoy many more years with my loved ones, and to share my story with the hope of empowering women of all backgrounds with the tools to overcome this disease.

About breast cancer

Breast cancer occurs when a malignant tumour (a group of cancer cells) begins to multiply uncontrollably in the breast and invade surrounding tissues. A malignant tumour, as opposed to a benign tumour, will metastasise (spread) to other areas of the body if left untreated, and will eventually cause death.³ The disease is related to the hormones estrogen and progesterone, and as such occurs mostly in women, and only rarely in men. Since the levels of these hormones rise and fall over a woman's lifetime, and are influenced by menarche and menopause, breast cancer is also related to the ageing process, occurring more frequently in post-menopausal woman than pre-menopausal women. Approximately two-thirds of invasive breast cancers occur in women over the age of 55.

We do not yet fully understand the exact causes of breast cancer. Nevertheless, researchers have identified certain risk factors that increase the likelihood of developing the disease, in

addition to ageing. Research suggests that between 5% and 10% of breast cancer cases are hereditary (the genes BRCA1 and BRCA2 are the most common causes of hereditary breast cancer).⁴ Other risk factors include a family history of breast cancer, alcohol consumption, being overweight or obese, and physical inactivity. Evidence also suggests that women who have never given birth, or gave birth to their first child after the age of 30 have a slightly increased risk of breast cancer. Conversely, breast-feeding appears to slightly decrease the risk of breast cancer. Still, it is important to keep in mind that not all women with one or more risk factors will develop breast cancer in their lifetime, and other women with no risk factors at all may develop the disease.

Often misconceived as a disease of rich women in rich countries, the reality is that cancer affects every corner of the earth and women of all ages. In 2012, 1.7 million new breast cancer cases were diagnosed worldwide; of which 883,000 were in less developed countries, and 794,000 in more developed countries.² Importantly, mortality from breast cancer is higher in poorer countries where health systems are weak, treatment costs are prohibitively high for the majority of the population, and the stigma attached to the disease is crippling.¹ Hence, while women in Australia, Europe and North America are more likely to get breast cancer (on a per capita basis), women in less developed countries are much more likely to die from it.

The diagnosis

Breast cancer is diagnosed on a scale of 0 to 4. Stage 0 refers to breast cancer that is 'non-invasive' (in other words, the cancer cells have not yet spread out of the area of the breast in which they started) and has a five-year survival rate of 100%.³ On the other end of the spectrum, stage 4 refers to 'invasive' breast cancer that has spread to other organs of the body such as the lungs, skin, bones, liver, or brain. This stage of cancer is the most developed and most lethal, and often referred to as 'advanced' or 'metastatic'.

The five-year survival rate for stage 4 cancer, with access to high-quality treatment, is 22%. Stages 1, 2, and 3 represent consecutively greater degrees of spreading, and have five-year survival rates of 100%, 93%, and 72% respectively.³ I was lucky enough to have caught the disease in its early stages, although this did little to reduce my anxiety at the time. I was plunged into a world of uncertainty, fear and anguish I can only liken to a nightmare (for more on my personal experience with breast cancer, see my memoir *Beauty Without the Breast*).

The treatment process

Compartmentalising my emotions was an important coping mechanism throughout my diagnosis and treatment. There was too much information, too much uncertainty; and while probabilities and survival rates are solid tools for analysing health systems, they are no solace in the face of a personal diagnosis of a potentially lethal disease. On the contrary, they create a labyrinth of unending possibilities, anguish and sheer terror. I could not will the cancer out of existence, and no amount of research could fully explain to me what was happening and what was going to happen. I could only imagine the fear and stigma faced by women with less means, less knowledge and less access to top-level health care than myself.

Depending on the type and stage of breast cancer, the therapy or treatment can be either local (treating the tumour on site) or systemic (treating the body as a whole through drugs administered orally or into the bloodstream that attack all cancer cells anywhere they may appear in the body). Local therapy includes surgery (a partial mastectomy that conserves a portion of the breast or a full mastectomy which removes the entire breast) or radiotherapy (targeted at the breast). Most women with breast cancer will undergo some type of surgery to remove the tumour. Systemic therapy includes chemotherapy, hormone therapy, targeted therapy and bone-directed therapy.⁵

When my doctor told me that I would have to undergo chemotherapy as part of my treatment, the image of my bald head overwhelmed me with fear and caused me to initially refuse the treatment. My rejection of chemotherapy was linked to my father's experience during the Holocaust. He had spent four years of his youth in a concentration camp and was the sole member of his family to survive the genocide. The idea of losing my hair and resembling the images of Holocaust victims engraved in my head since childhood was more than I could bear.

Ultimately, I realised that my fears were incomparable to those experienced by women all over the world facing a similar diagnosis to mine but who did not have the money to finance their treatment, who would have to impoverish their family to afford the treatment I was refusing, and who faced abandonment by their partner and stigma from their community. When I thought of these women and the unbearable social and health inequities of their circumstances, I knew that I could, and would, undergo whatever therapy was necessary. I also knew that I wanted to dedicate the rest of my life to being a voice for the millions of voiceless women facing this disease.⁶

Life post-breast cancer: living 'with' the disease

Perhaps the most important tool I developed during my treatment process which continues to serve me to this day was learning to recalibrate my expectations to the 'new me'. No matter how much I would like to be able to work the long hours I worked prior to my diagnosis, the reality is that I physically can no longer do so. Instead of forcing myself beyond my capabilities (which would be detrimental to my health now more than ever), being angry or disappointed with myself, I have learned to set new standards of excellence. The truth of the matter is that a diagnosis of breast cancer, even when treated successfully, sets off an early ageing process that can be mitigated but not reversed.

The side effects of breast cancer treatment include pain, fatigue, lymphedema, neuropathy, bone loss, sexual dysfunction, depression, fear of recurrence, cardiovascular disease, issues with memory, early menopause or menopausal symptoms (such as hot flashes and vaginal dryness), fertility issues and future cancer risk.⁷ Those who undergo chemotherapy may also experience weight gain and issues with cognitive functions (called chemo brain).

Personally, I tire more easily, have moments of memory loss and chemo brain, and have to live with varying degrees of pain almost every day. My 100% will never be what it was prior to my diagnosis, but it is important to recognise that I can still give my 100% and feel gratified in doing so. Indeed, there is a newfound serenity and pride that comes from achieving my goals, in spite of the pain, fatigue and the side-effects of medication. The 'new me' cannot sit for long hours because of the chronic back pain, but she is also mentally, emotionally and spiritually stronger than ever before. Focusing on the strengths I have gained as a result of my experience, as opposed to what I have lost, has not only been an invaluable coping mechanism, but also an important tool for personal development I likely would not have developed were it not for my disease.

To be sure, my work-life balance has improved significantly since my disease, as being faced with one's mortality brings into sharp focus what is truly important in life. The dread I felt upon my diagnosis was in fact not for my own life, but for my then 11-year-old daughter Hannah, and 3-year-old daughter Maha. The idea that they may have to witness my death at such tender ages and live their young lives without the presence and love of their mother was heart-wrenchingly painful. This made every day spent with them all that much more special. I now appreciate every moment with my girls with a consciousness and gratefulness I could not have known prior to my diagnosis. Furthermore, I am dedicated to instilling in them the strength that they provided me throughout my battle with cancer.

The early onset of menopause also has consequences for one's physical appearance and hence inevitably one's self-image. Breast cancer is not only an attack on your life, but an attack on your femininity (at least, as conceived by society). Even if a mastectomy is an effective medical means to an end (the removal of cancerous cells), there is no denying that it is also a lifelong test of self-acceptance. The breasts of a woman have long been revered as symbols of womanhood, desirability and beauty.

Having a disease in this most feminine of body parts, and then undergoing its removal, is of huge consequence for one's self-image. Here, again, I have learned to recalibrate expectations and to focus on what has been gained. During my treatment, I learned how to use make-up to highlight my blue eyes and high cheek-bones, bring colour to my lips, and to use all sorts of accessories – scarves, hats, and jewellery – to bring pizzazz to my look. I developed a newfound fondness for lipsticks of all shades and types. As a result, I have created a new self-image; one that I must confess is more myself than ever before, and one that I am proud to present to the world.

When I decided to write a memoir about my experience with breast cancer and was brainstorming titles for the book, my little Maha suggested 'Beauty without the Breast' — a play on the movie *Beauty and the Beast*. As she lit up with pleasure at her clever suggestion, I was overcome with an indescribable sense of joy and self-acceptance. I was, indeed, a beautiful woman; not because of my feminine body parts — which I had no part in creating anyway, but because of the bonds of love I had forged with my family and friends through which my beauty shone brightest, and because of the image I endeavoured to present to the world and to myself, in spite of my disease.

Living a healthy life as the best defense against relapse

Exercise

Engaging in regular exercise has been shown to reduce certain side-effects in breast cancer survivors, including fatigue, depression and

weight gain; to improve quality of life; as well as reducing the risk of recurrence.⁸ Personally, incorporating exercise into my daily routine has had significant effects on my mental health, physical strength and quality of life. It is important to keep in mind that getting regular exercise does not necessarily have to entail taking an hour out of your day to go to the gym. It is much more about leading a physically active life and incorporating fitness into your priorities and daily schedule. Walking, hiking, reading the newspaper on the treadmill at home before work, doing yoga by yourself or in a group, and taking a dance or aerobics class are all ways of incorporating fitness into your daily life.

When I began to make exercise a priority, I found that it was easy to multitask with other aspects of my life. For example, I now read up on the literature in my field every morning, as I have for years, but on my treadmill. I take conference calls while I take a brisk walk, and when taking vacations or attending conferences, I make sure to ask if the hotel has a gym or pool. Instead of taking the girls for ice cream or to the movies, we go for a walk, a jog, or horseback riding. In this way, I am not only strengthening my body and protecting it from a breast cancer recurrence, but I am also improving the quality of life for my whole family and teaching my daughters healthy lifestyle habits that will help to protect them in the long run too.

Healthy diet

While evidence shows that being overweight increases the risk of a breast cancer recurrence, even those who are not overweight can benefit from adopting a healthy diet.⁹ Although the jury is still out on the precise link between diets high in fat and breast cancer, there is no doubt that maintaining a diet that is high in fruits, vegetables and 100% wholegrains, while limiting the consumption of red meat, processed foods, and saturated and trans fats is part of a healthy diet that protects against different types of cancers, as well as other noncommunicable diseases. In addition, limiting consump-

tion of alcohol to less than one drink a day for women and avoiding tobacco use entirely is recommended for protecting against breast and other cancers.¹⁰ Most importantly, being mindful of the food and beverages we put into our bodies and the effects they have on our mental and physical state can not only protect us from developing a disease, but can significantly improve the quality of life of all and help us to be more present in all we do.

Mental health

Common side effects of breast cancer treatment include fear of recurrence, feelings of uncertainty and anxiety, depression, and impaired cognitive functions such as ‘chemo brain’. In dealing with the disease — during treatment and after — it is necessary to allow oneself to mourn the loss of the ‘old you’, and to allow oneself to honestly feel the spectrum of emotions that will undoubtedly emerge, including grief, depression, anxiety, stress, and anger. It is equally as important not to dwell on these emotions but to continually seek to improve one’s mental health. When it is not possible to overcome these feelings alone or with family members, it is crucial to reach out and seek help in the form of group therapy or from a professional. Although the evidence on the direct link between mental health and breast cancer outcomes is still inconclusive, there is no doubt that a positive mental attitude has huge effects on quality of life.

Furthermore, mental health should not be seen in a vacuum, but as a component of a healthy and social lifestyle that protects against disease. Social connections and contact with family, friends, colleagues and the community at large play a crucial role in speeding up the healing process post treatment and maintaining a positive attitude. Many breast cancer survivors have shared with me that talking to others with the disease or reading about other women’s experiences helped them get through the treatment process and afterwards. For me personally, fighting the stigma associated with breast cancer was a huge source of mental

strength. Not hiding my disease, but sharing my story with others, and being an example for other breast cancer patients and survivors provided me with a purpose and mental fortitude I did not know I had before.

Sexual health

There is an unspoken expectation that women who survive breast cancer ought to celebrate the fact that they are alive, and never complain about the repercussions on their physical appearance or sexuality. Yet, most women I have spoken with will admit in private that the sexual side-effects of breast cancer are a significant and ongoing challenge. They include: early onset menopause or menopause-like symptoms, vaginal dryness, loss of libido, as well as the myriad mental health and self-image issues that impact indirectly on sexual health.

I am lucky to have a loving partner who supported me unconditionally throughout my treatment process and to this day continues to see me as beautiful and desirable, and who showed infinite patience and affection in dealing with the issues surrounding intimacy. Unfortunately, this is not the case for most women. As is the case with mental health, it is critical not to feel ashamed and to seek the help of a professional — be it a doctor or therapist.

Although the sexual side-effects related to physical functions cannot be reversed, they can be managed; and the sexual side-effects related to self-image and mental health can be overcome through counselling. I am convinced that as more women who have lived through breast cancer speak openly about their experience, including the sexual health side-effects, this will begin to normalise the experience and destigmatise the disease as well as female sexuality. Reflecting on the challenges of fighting breast cancer, my husband Julio once wrote that stigma, discrimination, and machismo are the social cancers that keep women from screening for breast cancer early enough to make treatment effective.¹¹

Conclusion

My battle with breast cancer did not end with the completion of my treatment. I am reminded on a daily basis that I did not *have* breast cancer, but that I *live* with breast cancer. The downsides are the physical and psychological side-effects that follow me like a shadow and which I will have to manage for the rest of my life.

The upside is that my breast cancer gave me a new passion in life: a few weeks after my diagnosis, haunted by the images of women who did not have access to the same level of care, the support of a loving husband, and the means to finance treatment, I developed a program for breast cancer awareness in Mexico. This small program eventually developed into a civil society organisation, a Global Task Force on Cancer Care and Control in Low-and-Middle Income Countries, based at Harvard University, and a new line of research.

On a personal level, my breast cancer diagnosis marked the beginning of a period of personal growth and development. It taught me to live in the present; to appreciate the little moments with loved ones, the small victories as well as the large; and to lead a healthier, more balanced lifestyle. There is no doubt that the old me is gone, but I must admit that I quite enjoy living the ‘new me’.

Author note

This chapter is based on Dr Knaul’s personal testimony of her experience with breast cancer, originally published in Spanish as *Tomatelo a Pecho* (Mexico, DF: Aguilar Fontanar, 2009), and available in an updated English version as *Beauty Without the Breast* (Boston: Harvard Global Equity Initiative/Harvard University Press, 2012).

Endnotes

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