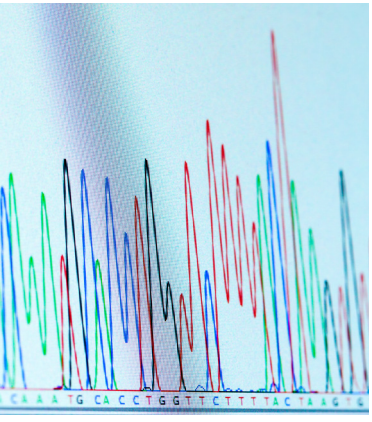
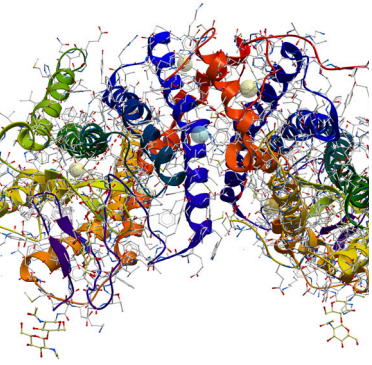
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A. Malcolm Campbell, *Editor*







Breast Cancer

Medical Treatment, Side Effects, and Complementary Therapies

K. V. Ramani
Hemalatha Ramani
Shirish S. Alurkar
B. S. Ajaikumar
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MOMENTUM PRESS, LLC, NEW YORK

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Breast Cancer: Medical Treatment, Side Effects, and Complementary Therapies

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First published in 2017 by
Momentum Press, LLC
222 East 46th Street, New York, NY 10017
www.momentumpress.net

ISBN-13: 978-1-94664-620-0 (paperback)
ISBN-13: 978-1-94664-621-7 (e-book)

Momentum Press Human Diseases and Conditions Collection

Cover and interior design by Exeter Premedia Services Private Ltd., Chennai, India

First edition: 2017

10 9 8 7 6 5 4 3 2 1

Printed in the United States of America.

Breast Cancer Patients and Their Caregivers

Abstract

A cancer prognosis has the tendency to knock the person and the family, off their feet. Nothing prepares one for the big "C." Soon after the diagnosis, it feels as if one has lost control of one's life, and nothing will be the same again.

A lot of the fear and dread associated with cancer is due to our lack of knowledge about the disease, its diagnostics, the treatment modalities, and the unexpected side-effects. There exists a lot of literature about cancer, but it is difficult for a lay person to understand.

This book describes the journey of Prema (diagnosed with breast cancer) and Prem (her caregiver), finding themselves in similar circumstances; immediate shock and helplessness, mad scramble for understandable information, struggling to understand and decipher it all, and finally deciding to fill that lacuna by writing this book.

This book covers the whole gamut of processes involved from the point of diagnosis till the woman is declared cancer free. It covers diagnosis, medical treatment options, physical and psychosocial side effects, complementary therapies, and the importance of patient-centered care to improve the quality of life of breast cancer survivors.

A conscious effort has been made to present all the required information, medical and non-medical, in simple language, without compromising the integrity of information. We hope future breast cancer patients, their caregivers, and families will benefit from our book and prepare themselves well to face the challenges of dealing with breast cancer.

Keywords

breast cancer, cancer staging, chemotherapy, depressions, immune system, lymph edema, lymph system, meditation, pain, patient-centered care plan, Yoga

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Foreword

You may have Cancer, but don't let Cancer have you! This is what this book on Breast Cancer (Ramani, Hema, et al) annotates. It serves as a ready reckoner for any cancer patient who wishes to open a new gateway to hope, positivity, love, and healing. Interestingly, this book swears allegiance to healing and thereby looks beyond the "cancer demon." This book is the result of personal trials and tribulations of Prema (breast cancer patient) and Prem (her husband and primary caregiver) from the day Prema was diagnosed with cancer, and their successful survivorship of the disease, physically, emotionally and mentally; mind, body, and soul.

Most cancer patients mechanically go through their treatments without much active participation in their own healing; not being aware of the drug, its mechanism of action, the nature of the scans, or the uncertainty of the outcomes. By taking the readers through the real-life breast cancer journey of Prema and Prem, the authors have succeeded in providing a fair amount of information about cancer as a disease that affects both the body and the mind. The authors elucidate how a cancer patient's active participation in her treatment helps to fight the cancer and heal the physical and emotional side effects.

Knowledge helps shine a bright light on the disease and dissipates some of the associated darkness. This book hopes to be that light.

—Dr (Prof) Vishal Rao U.S.;
Consultant Oncologist—Head & Neck Surgeon,
Chief—Head & Neck Services, Department of Surgical Oncology,
HealthCare Global (HCG) Cancer Centre
Associate Editor—Cancer Therapy & Oncology
International Journal
Recipient of the Judy Wilkenfeld Award for Excellence in
Global Tobacco Control;
WHO; 2017.

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Preface

"Patient-Reported Cancer Quality Theme: Provide information to help patients and families find reputable websites; navigators to help patients participate in decision-making; knowledge of how to manage side effects; care team helping patient to understand diagnosis; written information on what to expect during treatment, side effects, and what to do at home; knowing who to ask when there are questions

Barriers: patients overwhelmed by amount of, complexity of, and conflicts in information; patient education provided after major decisions have been made; lack of awareness of what was going to happen, procedures not explained; not understanding test results; contradictory information; not knowing where to call after hours"

—Lisa M Hess and Gerhardt Pohl
Perspectives of Quality Care in Cancer Treatment:
A Review of the Literature;
Am Health Drug Benefits. 2013 Jul-Aug; 6(6): 321–29.

The above observations by Hess and Pohl highlight community expectations as an important indicator of cancer service quality. Cancer patients, their families, and caregivers now expect comprehensive information about cancer, its treatment, and side effects in order to be participants in the decision making of their treatment options.

Our book is an attempt to provide simple and comprehensive information about breast cancer. This would facilitate informed decision making by patients, their families, and caregivers regarding the long-drawn-out nature of breast cancer treatment and care. We have done an extensive literature review of journal articles on cancer care; accessed reliable websites (World Health Organization [WHO], National Institutes of Health [NIH], National Health Service [NHS], National Cancer Foundation, etc.); and also met cancer survivor groups who have walked the cancer journey.

The chapters in our book relate to breast cancer, diagnosis, test results, treatment options, side effects, and quality of life during and after medical treatment. Chapter 1 provides an understanding of cancer. Chapters 2 to 4 focus on educating breast cancer patients, their families, and caregivers on what breast cancer is, its diagnosis, test results, and treatment options. Chapters 5 to 7 focus on the physical, mental, and emotional side effects of breast cancer and the role of complementary therapies in recovering/healing and establishing internal mind, body, and soul balance so as to improve the quality of life during and after medical treatment. Chapter 8 focuses on the importance of patient-centric treatment and care plans to improve the quality of cancer care. Chapter 9 presents our concluding remarks.

We hope that this book will meet the community needs of breast cancer patients, their caregivers, and families to understand breast cancer and enable them to participate in decision making at all stages in the continuum of cancer care and improve the quality of life of cancer survivors.

—Ramani, Hema, Alurkar, Ajaikumar, Riri

Acknowledgments

We would like to thank the Indian Institute of Management, Ahmedabad, India, for all the support extended to us in writing this book.

The very hard, long drawn, exhausting, yet dignified journey of Breast Cancer Survivor, Prema, and her husband/Primary Care-giver, Prem, was the inspiration for this book. The trying and unpredictable circumstances they had to face every step of the way got the authors thinking about the need for this book. We, the authors, would like to tip our hats off to and thank all the Premas and Prems around the world, who make this journey.

CHAPTER 1

Understanding Cancer

What is Cancer?

We often hear people say, "Fight cancer," but not "Fight diabetes" or "Fight heart diseases." Is there any specific reason to be afraid of cancer, as opposed to other diseases? Not really. Cancer is like any other chronic[1] disease (such as heart disease, respiratory disease, kidney failure, diabetes, and so on) with one major difference: Cancer is a disease of both the body and mind.

Cancer is a disease of the body because cancer is diagnosed when some cells in the body turn into cancerous cells. Medical treatment (a combination of surgery, chemotherapy, and radiotherapy) is necessary to kill the cancer cells and minimize their chance of recurrence. There is no other scientifically proven approach to kill cancer cells.

Cancer is also a disease of the mind. Emotional sufferings (such as fear of cancer) start in the mind and cascade through our body via stress responses in many forms (Rankin 2013).[2] Stress symptoms can affect the body (such as tiredness and sleeplessness), mood (such as anxiety and depression), and even behavior (such as angry outbursts and social withdrawal)[3] and thereby affect the mind–body balance. Complementary

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[1] As per the U.S. National Center for Health Statistics, chronic diseases are long-term (more than 3 months) medical conditions that are generally progressive. Chronic diseases generally cannot be prevented by vaccines or cured by medication, nor do they just disappear. Chronic diseases have a range of potential impacts on the quality of life as well as broader social and economic effects.

[2] Rankin, L. 2013. *Mind Over Medicine: Scientific Proof That You Can Heal Yourself*. Carlsbad, CA: Hay House.

[3] Stress Symptoms: Effects on Your Body and Behavior
http://mayoclinic.org/healthy-lifestyle/stress-management/in-depth/stress-symptoms/art-20050987

therapies (like yoga and meditation) do help in recovering and establishing the mind–body balance. The old saying "State of the mind dictates the state of the body" cannot be better illustrated elsewhere.

The human body is made up of trillions of cells. Each cell contains 23 pairs of chromosomes in its nucleus, each pair having one chromosome from the father and one from the mother. Each chromosome contains hundreds to thousands of genes, made up of a chemical DNA. The Human Genome Project[4] estimated about 25,000 protein-coded genes in our body. Proteins are required for the structure, function, and regulation of the body's activities.

Cells form tissues, tissues form organs (heart, lungs, breasts etc.), and organs form organ systems (cardiovascular system, respiratory system, etc.). The process of cells forming tissues and tissues forming organs is the result of each cell growing in size and dividing into two identical cells, two cells into four identical cells, four cells into eight, and so on. The DNAs in each cell control the process of division and multiplication of cells into identical cells in a controlled manner.[5]

At times, some cells get "injured" (e.g., by chemicals in tobacco smoke). Each cell has the ability to repair the damages to the DNA before it divides and multiplies, but sometimes a cell's ability to make these repairs fails. As the cell injuries, known as cell mutations,[6] build up

---

[4] The Human Genome Project: National Human Genome Research Institute, National Institutes of Health (NIH); https://genome.gov/11006943/human-genome-project-completion-frequently-asked-questions/
A genome is an organism's complete set of DNA, a chemical compound that contains the genetic instructions needed to develop and direct the activities of the organism. DNA molecules are made of two twisting, paired strands of four chemical units. The human genome contains approximately 3 billion of these base pairs, which reside in the 23 pairs of chromosomes within the nucleus of all the cells.

[5] Cells of different tissues and organs divide at different rates. For example, skin cells divide relatively quickly, whereas nerve cells divide very slowly or not at all once they mature. Ref: Cancer Cell Development; http://cancer.ca/en/cancer-information/cancer-101/what-is-cancer/cancer-cell-development/?region=on

[6] Mutations can affect the structure of the gene and stop it from working properly. Some mutations do not affect the critical areas of a gene (DNA) and may not

over time, some of the damaged cells become malignant[7] and grow in an uncontrolled manner. Cancer therefore develops because of mutations (changes) that take place in an uncontrolled manner in a person's DNA, the genetic blueprint.

Cancer is thus a complex disease and can be broadly classified into three categories:

i. Carcinomas are cancers that develop in epithelial cells.[8] About 80 to 90 percent of cancers, mostly lung, breast, prostate, and bowel cancers are carcinomas.
ii. Sarcomas are cancers that develop in the connective tissues.[9]
iii. Leukemia and lymphomas are cancers that develop in the blood or lymphatic system.[10]

---

cause a problem, but other mutations do. Mutations can happen by chance when a cell is dividing. They can also be caused by the processes of life inside the cell. Or they can be caused by chemicals from outside the body, such as chemicals in tobacco smoke. And some people can inherit faults in particular genes that make them more likely to develop a cancer. Ref: How Cancer Starts: http://cancerresearchuk.org/about-cancer/what-is-cancer/how-cancer-starts

[7] Tumors can be either benign or malignant. Benign tumors are not cancerous and do not spread to other parts of the body. Malignant tumors are cancerous; they could invade nearby tissues and spread to other parts of the body.

[8] Epithelial cells form the covering of other cells, tissues, and all the organs and hence are present in skin, scalp, and so on.

[9] Connective tissue makes up a connective web inside our body to hold our body parts together and provide support. Other types of tissues in our body are muscle tissues, epithelial tissues, and nerve tissues. Muscle tissue is made up of cells that are long and fibrous, ready for contraction, or the activation of tension in our muscles, making it possible for us to move our body parts. Epithelial tissue, made up of epithelial cells, makes an excellent protective cover for the body, in the form of skin. Nerve (nervous) tissue is found within the nervous system and is made up of nerve cells called neurons, which transmit signals from nerves to the spinal cord and brain for us to use our senses.

[10] Lymph is mostly blood plasma left behind on the tissues by the blood circulatory system after bathing and nourishing them. Lymph is carried by the lymphatic system and returned to the blood circulatory system. See Chapter 2 Exhibit 2.1 for an explanation of the lymphatic system.

Mind–Body Connection

As mentioned earlier, cancer is a disease of the mind and body. Cancer and cancer treatments have an impact on the mind–body connection. The state of mind changes the state of the body by working through three important systems[11] in our body, namely, the endocrine system, the immune system, and the central nervous system.

The impact of mind–body connection is manifest in the form of physical side effects, emotional issues, and social problems. Physical side effects include loss of an organ, fatigue, pain, loss of appetite, loss of interest in sex, sleeping problems, and so on. Emotional issues include fear, worry,

---

[11] Ref: The Endocrine System: An Overview; https://ncbi.nlm.nih.gov/pubmed/15706790

Immune Systems Research; National Institute of Allergy and Immune Diseases; www.niaid.nih.gov/research/immune-system-research

Nervous System; https://ncbi.nlm.nih.gov/pubmedhealth/PMHT0025454/

The endocrine system is a collection of glands that secrete hormones into the blood. These hormones, in turn, travel to different tissues and regulate various bodily functions, such as homeostasis (the internal balance of body systems), metabolism (body energy levels), reproduction, and response to stimuli (stress and/or injury). The sex hormones (e.g., estrogen and progesterone) are the type of hormones most commonly affected by cancer and its treatment. Low levels of sex hormones (e.g., during menopause) can lead to side effects such as hot flushes and sweats, memory changes, weaker bones, and sleep change.

The immune system is a network of cells, tissues, and organs that work together to protect the body from infections against harmful influences of pathogens like bacteria, viruses, parasites, and fungi. Our immune response is divided into innate and adaptive immune systems. Innate immunity refers to immune responses that are present from birth. Acquired (adaptive) immunity is the immunity that our body gains over time (e.g., from vaccinations). The acquired immunity system stores the information about each specific pathogen it encounters and uses this information to provide future immunity from pathogens of the same kind.

The nervous system has two parts, called the central nervous system (CNS) and the peripheral nervous system (PNS) due to their locations in the body. PNS is further divided into the somatic nervous system (SNS)and the autonomic nervous system (ANS). SNS controls voluntary functions such as movement of the muscles and organs and reflex movements. ANS regulates involuntary functions, such as blood pressure and the rate of breathing, automatically without us being conscious.

Ref: www.niaid.nih.gov/research/immune-system-research

depression, anger, sadness, and anxiety. Social life changes include financial stress, workplace identity issues, stigma, and isolation. It is important to note that both the patients and their caregivers face emotional issues and social life changes during and even after treatment.

Cancer and its treatment are unique in that they impact the body, the mind, and thus, emotions. Coping with cancer is not about coping with the illness alone. The physical side effects are intrinsically interwoven/linked to emotional, psychological, and social issues, which can show up even many years after treatment is completed.

Burden of Cancer

As per the World Health Organization (WHO) World Cancer Report 2014,[12] the number of new cancer cases globally has gone up from 10 million in 2008 to approximately 14 million new cases of cancer by 2012, and the number is projected to be around 20 million new cancer cases each year by 2025. The highest rates of new cancer cases per year are associated with high-income countries of North America and Western Europe, along with Japan, Australia, and New Zealand. However, the total number of cancer cases is high in Asia, Africa, and Central and South America; these countries have large population and probably cancer is typically diagnosed at more advanced stages of the disease.

Almost 90 to 95 percent of all cancer cases can be attributed to the environment and lifestyle;[13] lifestyle factors include cigarette smoking,

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[12] World Cancer Report, 2014; http://who.int/cancer/publications/WRC_2014/en/ The World Cancer Report is based on GLOBOCAN 2012 data. GLOBOCAN is the web portal for the International Agency for Research on Cancer (IARC) under the WHO. The World Cancer Report provides a unique global view of cancer, including cancer patterns, causes, and prevention. The World Cancer Report series is recognized as an authoritative source of global perspective and information on cancer. The first volume appeared in 2003, the second in 2008, and the third in 2014.

[13] Anand, P., A.B. Kunnumakara, C. Sundaram, K.B. Harikumar, S.T. Tharakan, O.S. Lai, B. Sung, and B.B. Aggarwal. 2008. "Cancer is a Preventable Disease that Requires Major Lifestyle Changes." *Pharmaceutical Research* 25, no. 9, pp. 2097–116.

diet (fried foods, red meat), alcohol, sun exposure, environmental pollutants, infections, stress, obesity, and physical inactivity. Cancers are age related,[14] much more frequent in the old than in the young. As per a recent study by the National Cancer Institute[15] of the National Institutes of Health, U.S.A., about 50 percent of all new cancer cases (all cancer sites) are diagnosed in the age group 55 to 74 years. This phenomenon may change over a period of time as a result of changes in lifestyle.

The economic burden of cancer is very significant. The economic burden has two components, namely, direct costs and indirect costs. Direct costs include hospitalizations, consultations, surgery, chemotherapy, radiotherapy, and prescription drugs. The Agency for Healthcare Research and Quality (AHRQ),[16] American Cancer Society, estimated that the direct medical cost (total of all health care cost) for cancer in the United States in 2011 was $88.7 billion. About 50 percent of the cost is for hospital outpatient or doctor office visits, 35 percent of the cost is for inpatient hospital stays, and 11 percent of the cost is for prescription drugs. Indirect costs are associated with the impact of the disease on the patient, caregivers, and the society. The national economy suffers from productivity loss through lost wages of the patients and their caregivers, as well as from premature deaths. As per the WHO fact sheet on cancer, an estimated 169.3 million years of healthy life were lost globally in 2008. It is important to realize that the economic cost of cancer in developing countries will be much higher due to the higher number of cancer patients and delayed diagnosis.

---

[14] As cancer is age related, it would be necessary to provide age-standardized estimates of cancer incidence and prevalence. This is all the more important since the age structure of the cancer registry population varies across countries. For example, Japan has 33 percent of its population above the age of 60, while India has only 10 percent of its population in the same age group. Age-standardized rate (ASR) is a summary measure of the rate that a population would have if it had a standard age structure.

[15] Age, National Cancer Institute; https://cancer.gov/about-cancer/causes-prevention/risk/age

[16] Economic Impact of Cancer: American Cancer Society. Cancer Facts & Figures 2015, Atlanta, Ga. 2015; http://cancer.org/cancer/cancerbasics/economic-impact-of-cancer

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Cancer Prevention

> Cancer prevention is action taken to lower the chance of getting cancer. In addition to the physical problems and emotional distress caused by cancer, the high costs of care are also a burden to patients, their families, and to the public. By preventing cancer, the number of new cases of cancer is lowered. Hopefully, this will reduce the burden of cancer and lower the number of deaths caused by cancer.[17]

Societal, economic, and lifestyle changes would continue to have profound effects on the scale and profile of cancer burden, and thereby there is a need for tailored and effective strategies for cancer control, treatment, and prevention.

Types of Cancer

Cancers are named after the sites where they start growing. An estimate of the number of cancer cases by cancer site (all ages) based on GLOBOCAN 2012 data is given in Table 1.1.

It can be seen that breast cancer is the most common type of cancer among women with cancer.

Conclusion

In the next two chapters (Chapters 2 and 3), we discuss breast cancer (the most common site of cancer in women) and its diagnosis. While medical treatments (surgery, chemotherapy, and radiotherapy; see Chapter 4) kill the cancer cells, they could cause physical and emotional side effects (such as pain, fear, and depression) during and after treatment, which severely affect the quality of life of cancer survivors. A discussion on physical and emotional side effects and suggestions to manage them are included in

---

[17] National Cancer Institute, National Institutes of Health; Cancer Prevention Overview; www.cancer.gov/about-cancer/causes-prevention/patient-prevention-overview-pdq

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Table 1.1 Estimated number of Cancer cases (all ages): 2012

Cancer type	Women (%)	Men (%)	Both sexes (%)
Breast	25.2		11.9
Cervical	7.9		3.7
Prostate		15.0	7.9
Lung cancer	8.7	16.7	13.0
Colorectum*	9.2	10.0	9.7
Stomach	4.8	8.5	6.8
Liver	3.4	7.5	5.6
Others	40.8	42.3	41.4
Total	100 %	100 %	100 %

Source: World Cancer Report, 2014: World Health Organization

* Colorectum/*colorectal cancer*, also known as bowel *cancer*, colon *cancer*, or rectal *cancer* is any *cancer* (a growth, lump, tumor) of the colon and the rectum.

Chapters 5 and 6. Importance of complementary therapies (such as yoga and exercises) in improving the quality of life (by establishing the mind–body connection) is discussed in Chapter 7. Complementary therapies are in addition to medical treatment and NOT a substitute, since medical treatments and complementary therapies address different (complementary) issues in cancer treatment and care. The last chapter in this book (Chapter 8) highlights the importance of patient-centered care, rather than doctor-centered care, in the continuum of cancer treatment and care. Patient-centered care focuses on the aspirations of the "person" without compromising on the quality of care.

There is plenty of good news for cancer care. Medical developments in the diagnosis and treatment of cancer have led to earlier diagnosis and more cancer survivors. This trend is continuing without compromising on the quality of treatment or the quality of life during and after treatment.

CHAPTER 2

Breast Cancer

Case Study: Journey of Prema (Part 1)

April 8, 2010, started like any other day for Prema. Prema and her husband Prem went for their annual health checkup like they had been doing for decades, except for the previous year 2009. Little did they know what was in store for them, and the next 24 hours would change Prema's life in many ways. The gynecologist's physical exam found a lump in her left breast and another in her left armpit. Just the looks of the gynecologist said it all: CANCER. The mammogram and sonography confirmed breast cancer and Prema's life literally turned on its head. Her first thoughts were how to tell her mother aged 80+ years and her two sons. Prema felt very lonely; only her husband Prem was with her—her only sibling, mother, and both the sons were abroad. People whom Prema informed about the prognosis often asked her, "Why you?" Honestly, Prema never asked that question. She was more focused on the "given" and not on questions for which there were no answers. Prema and Prem needed to quickly accept the prognosis and plan for the medical and financial implications. Her motto became, "I have cancer, cancer doesn't have me." Her team of oncologists were all very happy to answer any question, but Prema and Prem realized that it was up to them to educate and prepare themselves because of the nature of the disease. They trawled the Internet to collect whatever information was available, whether concerning what breast cancer is, what causes it, the results of investigations, the treatment modalities, or the various side effects.

Prem took leave for six months from work to become Prema's primary caregiver.

Understanding Breast Cancer

Cancer is usually named after the part of the body where cancer cells start growing (primary site)**.** Breast cancer is therefore a cancer of the breast; it is the transformation of some breast cells into a malignant tumor.[1] Breast cancer can occur in both men and women; the vast majority of breast cancer cases (almost 99%) occur in women.

In a female, breast tissues develop as part of the puberty process. Before puberty, the breast consists mainly of fat tissues. After puberty, the breast develops glands, which can secrete milk. The breast of a mature female consists of fat, connective tissues (stroma), and thousands of tiny glands (lobules). Milk produced in the lobules is carried by tiny tubes (ducts) to the nipple (Figure 2.1). Thus, the breast has a network of interconnecting ducts and lobules that ultimately converge to the nipple.

Breast cancer can be broadly classified into two types.

- **Ductal carcinoma** begins in the milk duct, the most common type of breast cancer.
- **Lobular carcinoma** that begins in the lobules and is much less common.

Breast cancer cells could fall into any of the following categories:

- Noninvasive
- Invasive
- Metastatic

Breast cancer cells are

[1] A tumor is a mass of abnormal tissues. Tumors are either benign or malignant. Both benign and malignant tumors are the outcomes of abnormal growth of body cells. Benign tumor is not cancerous as it does not spread to other areas of the body. Malignant tumor is cancerous, could spread to other areas/parts of the body, and so must be removed.

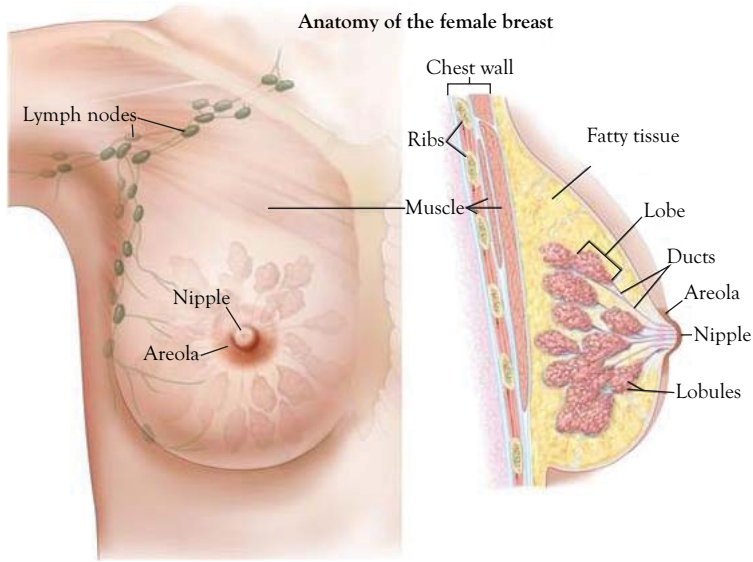


Figure 2.1 Female breast and lymph nodes

Source: National Cancer Institute (https://www.cancer.gov); Most recently accessed on April 12, 2017

- Noninvasive if the abnormal cells that start growing in the lining of the breast milk duct or lobules have not spread to the surrounding breast tissues (stay within the lobules/ducts)
- Invasive if the cancer cells that start growing in the milk ducts or lobules of the breast spread beyond the ducts/lobules and invade the fatty breast tissues and probably to nearby lymph nodes[2] in the armpit (see Figure 2.1) but not distant organs

[2] Lymph Node Involvement: http://breastcancer.org/symptoms/diagnosis/lymph_nodes
Lymph (mostly blood plasma) is the fluid left behind on the tissues by the blood circulatory system after bathing the tissues and nourishing them. Lymph flows through lymph nodes, which are small, bean-shaped organs that act as filters along the lymph fluid channels, and eventually joins the bloodstream. Having cancer cells in the lymph nodes under the arm suggests an increased risk of the cancer spreading.

- Metastatic (spread to other parts of the body, mostly lungs, bones, or brain) if the breast lymph nodes become malignant, as explained in the following text

The lymph, lymph vessels, lymph nodes, and lymph organs make up the lymph (lymphatic) system.[3] The lymph system transports lymph through lymph nodes, lymph vessels, and lymph trunks (larger lymph vessels) and returns it to the blood circulatory system. Malignant breast lymph nodes could therefore spread malignant cells to other parts of our body through the blood circulatory system[4] or the lymph system.

Symptoms

The most common symptom of breast cancer is a new lump or mass. Other possible symptoms of breast cancer include[5]

---

[3] The lymph system performs three important functions: (i) maintains fluid balance, (ii) provides immunological defense, and (iii) distributes dietary fats to the bloodstream. Cancer and cancer treatments are likely to affect the normal functioning of the lymph system leading to physical and emotional side effects. For a detailed discussion on the lymph system and breast cancer, we refer you to Exhibit 2.1.

[4] The blood circulatory system, comprises the blood, heart, and blood vessels, distributes blood, nutrients, oxygen, carbon dioxide, and hormones around the body. Blood is a fluid made up of four separate components:

1. The red blood cells (RBCs) carry oxygen to all parts of the body and remove carbon dioxide. By volume, the RBCs constitute about 40 to 45 percent of whole blood.
2. White blood cells (WBCs) help the body fight infection.
3. Platelets are small blood cells, which help wounds heal and prevent bleeding by forming blood clots.
4. Plasma is mostly water (92% by volume) and contains dissipated proteins, glucose, mineral ions, hormones, and so on. Plasma constitutes 55 percent of blood fluid, and it helps maintain blood pressure and regulates body temperature

[5] Breast Cancer Signs and Symptoms; American Cancer Society
http://cancer.org/cancer/breastcancer/detailedguide/breast-cancer-signs-symptoms

- Swelling of all or part of a breast (even if no distinct lump is felt)
- Skin irritation or dimpling
- Breast or nipple pain
- Nipple retraction (turning inward)
- Redness or thickening of the nipple or breast skin
- Nipple discharge (other than breast milk)
- Occasionally, cancer presents with signs and symptoms of metastases, for example, severe backache (spread to spine), persistent cough (spread to lungs), or headache (spread to the brain)

Risk Factors

A risk factor is something that may increase the chance of getting cancer. We list in the following text a few risk factors for breast cancer. It is important to realize that a woman with a risk factor does not necessarily develop breast cancer while a woman without any risk factor could still develop breast cancer.[6]

1. Dense breast: Dense breast tissues make lumps harder to detect through mammograms.
2. Aging: The risk for developing breast cancer increases with age, even though the number of young women (<40 years) getting breast cancer is increasing
3. Personal health history: Long-standing benign (noncancerous) breast disease, and/or noninvasive ductal carcinoma
4. Family history: A first-degree relative in the family having breast cancer (sister, daughter, mother, maternal aunt, father, or brother) increases the risk of developing breast cancer. A family may have members affected with breast and ovarian cancers and such cases usually have an abnormal cancer-predisposing gene called BRCA-1 and BRCA-2 (known as breast cancer gene). Women with BRCA-1

[6] National Breast Cancer Foundation (NBCF); USA; http://nationalbreastcancer.org/breast-cancer-risk-factors

mutation have an 80 to 85 percent lifetime risk of developing breast cancer

5. Menstrual history: Early menstruation and late menopause lead to a prolonged exposure to estrogens in menstrual cycles. The menstrual cycle is regulated by the estrogen and progesterone hormones produced by the pituitary endocrine gland in the endocrine system
6. Reproductive history: Use of estrogen-containing medications (certain birth control pills) to delay pregnancy. Women who do not have children or have given birth after the age of 30 years
7. Environmental/lifestyle factors such as

- Lack of physical activity: Regular physical activities are required to maintain a healthy weight. Excess weight leads to high levels of estrogen production in the body, which is a cancer risk.
- Obesity: One of the strongest links between obesity and cancer is an increased risk of breast and womb cancers in women who are overweight or obese after menopause. This is because ovaries stop producing estrogen after menopause and fat cells take over. Estrogen produced by fat cells can make breast cells divide and multiply much faster.
- Alcohol consumption: Estrogen levels are higher in women who drink alcohol than in nondrinkers. These higher estrogen levels may, in turn, increase the risk of breast cancer.
- Exposure to natural background radiation: Background radiation is harmful ionizing radiation (high levels could increase cancer risk) present in the environment. Natural high background radiation is high in the coastal areas of Kerala and Tamil Nadu states.
- Radiation (to the chest) from medical devices: Medical devices such as x-ray and computed tomography (CT) scans for treatment produce harmful ionizing radiation.
- Hormone replacement therapy (HRT): HRT is a treatment used to relieve symptoms of menopause, such as hot flashes,

mood swings, and night sweats. HRT uses exogenous hormones (e.g., estrogen) to manage menopausal symptoms. High amounts of estrogen in the blood may increase a woman's breast cancer risk.

Myths and Misconceptions

A few common myths about breast cancer are listed in the following text (Table 2.1). Myths numbered 1 to 7 are taken from the NBCF website.[7]

Conclusion

In this chapter, we have explained breast cancer, types of breast cancer, risks, and myths about breast cancer. In the next chapter, we discuss several investigations and tests to diagnose breast cancer. It is important to mention here that early detection of breast cancer has a high chance of a permanent cure.

Table 2.1 Breast cancer myths

No.	Myth	Truth
1	Finding a lump in your breast means you have breast cancer	Only a small percentage of breast lumps turn out to be cancerous
2	Men do not get breast cancer; it affects women only	A small percentage of men get it. Male mortality is higher than female mortality from breast cancer
3	A mammogram can cause breast cancer to spread	A mammogram currently remains the gold standard for the early detection of breast cancer
4	Radiation from mammogram causes cancer	Radiation dose from mammogram is very low and hence safe
5	If you have a family history of breast cancer, you are likely to develop breast cancer too	Statistically only about 10% of individuals diagnosed with breast cancer have a family history of this disease
6	Breast cancer is contagious	NO

(*Continued*)

[7] Myths: http://nationalbreastcancer.org/breast-cancer-myths

Table 2.1 (Continued)

No.	Myth	Truth
	If the gene mutation BRCA1 or BRCA2 is detected in your DNA, you will definitely develop breast cancer (BRCA: **BR**east **CA**ncer genes)	Regarding families who are known to carry BRCA1 or BRCA2, Not every woman in such families carries a harmful BRCA1 or BRCA2 mutation, and not every cancer in such families is linked to a harmful mutation in either of these genes
7	Antiperspirants and deodorants cause breast cancer	Not aware of any conclusive evidence on this subject
8	Needle biopsy for diagnosis would induce a tumor to spread to distant parts of the body	No evidence exists for breast cancer
9	Removing a breast will reduce sexual drive	No biological evidence, as hormones are produced in the ovaries
10	Mammograms prevent breast cancer	Regular mammogram facilitates early detection of cancer; early cure saves lives
11	Most breast lumps are cancerous	Only 10–29% of breast lumps are cancerous
12	If mammography report is negative, there is nothing to worry about	Mammograms fail to detect cancers in 10–20% of the cases. False-positive and false-negative reports do occur.

Exhibit 2.1 Lymph system and breast cancer

The lymph system consists of lymph, lymph vessels, lymph nodes, and lymph organs.

Lymph

Lymph is produced in the body as follows. Blood flows from the heart to different parts of our body through arteries, arterioles (thinner arteries), and capillaries (the smallest of all blood vessels). The capillaries retain the blood cells (RBCs, WBCs, and platelets) and release the plasma (a colorless fluid) into the surrounding tissues. This fluid, which contains oxygen, glucose, amino acids, and other nutrients bathes the tissue cells, nourishes them, and removes the waste products. About 80 to 90 percent of the filtered fluid is reabsorbed directly into the capillary blood vessels and reenters the blood circulatory system. The remaining 10 to 20 percent of

the fluid enters the lymphatic system through lymphatic capillaries. The fluid in the lymphatic system is called lymph.

Fluid Balance

The vast network of lymph vessels carry the lymph fluid[8] through lymph nodes and deposit them into two large lymph ducts on either side of the neck. These ducts *drain* the lymph into subclavian veins (large veins under the clavicle or the collarbone) as plasma. Subclavian veins, like other veins, carry the blood into the heart. Thus, the lymphatic system returns the lymph fluid to the blood circulation system and thereby maintains the fluid balance in our body.[9]

Immunological Defense

The lymphatic system is part of the broader immune system.[10] The immune system includes a variety of defenses against viruses, bacteria, fungal infections, and parasites. The lymph nodes and lymph organs (e.g., thymus, spleen, and tonsils) play an important role in the immune system.

Lymph Nodes

Hundreds of lymph nodes are found in and around many parts of our body. The lymph nodes contain different types of WBCs, which fight infection by attacking and destroying germs that are carried through the lymph and filter the harmful substances.

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[8] Lymph flows only in one direction, toward the neck region.

[9] Recall that lymph is the 10 to 20 percent of blood plasma left behind on the tissues by the blood capillaries, while 80 to 90 percent of the blood plasma flows back into the blood capillaries and enters the blood circulatory system. Thus the lymphatic system maintains fluid balance in our body.

[10] The immune system is a network of cells, tissues, and organs that work together to protect the body from infection.

Lymph Organs

Lymph organs such as the spleen, thymus, and tonsils play an important role in the immune system (Figure 2.2).

- *Spleen, located on the left upper abdomen,* is the largest lymphatic organ and is responsible for both the storage and purification of RBCs and helps to fight infection.
- *Thymus gland* is the main organ of the lymphatic system. Located in the upper chest region, its primary *function* is to promote the development of specific cells of the immune system called T lymphocytes. They also protect the body from itself by controlling cancerous cells.
- Tonsils are located on each side of the back of the throat. They facilitate adaptive immune responses in the upper respiratory tract, which is one of the most common pathways for pathogen entry in the body. An infected tonsil is called tonsillitis.

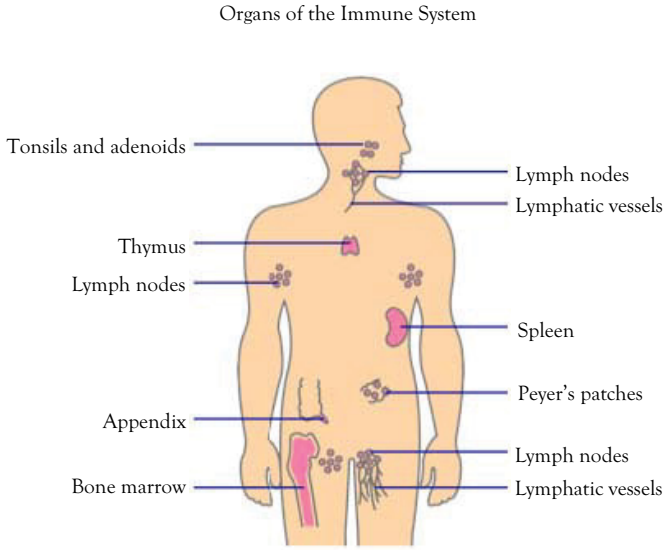


Figure 2.2 Organs of the immune system

Source: National Cancer Institute (https://www.cancer.gov); Most recently accessed on April 12, 2017

Transports Dietary Fats to Bloodstream

Fats, carbohydrates, and proteins are the three macronutrients required by our body to produce energy. The lymphatic system plays an important role in transporting the fat (from the food we eat) from the intestine to all parts of our body.[11]

A compromised lymph system (e.g., removal of lymph nodes) could affect the fluid balance (leading to swelling, lymph edema; more in Chapter 5), reduce immunity, and/or affect the lipid profile.

[11] The cells lining the intestine pack the fats into large spherical objects (chylomicrons). Unfortunately, these packs are too big to be diffused into the blood capillaries for direct absorption by the body. These (fats) are therefore, absorbed by the lymphatic system in the intestine, routed through the lymphatic vessels (lacteals), and finally delivered to the blood circulatory system via the left subclavian vein. Once in the circulatory system, fats are distributed to all parts of the human body. Note that all lipoproteins (and therefore chylomicrons) contain cholesterol. Hence we talk of cholesterol and fat together. The transport of fat and cholesterol in the blood has major health considerations.

CHAPTER 3

Breast Cancer: Investigations and Diagnosis

Case Study: Journey of Prema (Part 2)

Prema's mammogram and sonograms showed an irregular solid mass lesion in upper and outer quadrant of left breast and also an enlarged left axillary node. She was assessed as Breast Imaging Reporting and Data System (BIRADS)-4C; suspicious finding. The radiologist recommended a biopsy for tissue diagnosis.

A core needle biopsy was performed on the left upper quadrant breast lump. Histopathology test reported malignant tumor, invasive and in situ lobular carcinoma, Grade 3.

Immunohistochemistry tests for hormone receptors established that Prema's breast cancer was estrogen receptor (ER) strongly positive around 95 percent, progesterone receptor (PR) strongly positive around 95 percent, and *human epidermal growth factor receptor 2* (HER2 neu) was estimated at level 2+.

All the tests and investigations described earlier provided a fair amount of information to plan her treatment. But the oncologist suggested a positron emission tomography (PET)/computed tomography (CT) scan to understand the stage of the malignant tumor, so that all the necessary information would be available for the tumor board at the hospital to design an evidence-based treatment plan for Prema.

Prem was back to surfing the Internet to understand the various screening and diagnostic investigations for breast cancer and understand the results of investigations. He found the team of oncologists at the hospital very helpful to clarify his concerns, which arose frequently.

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Mammogram

Mammography is the study of breast using x-rays. A mammogram is an x-ray of the breast, which shows the fatty, fibrous, and glandular tissues. Screening mammograms are routinely administered (in annual health checkups) to detect breast cancer in women who have no apparent symptoms. Doctors use a mammogram to look for early signs of breast cancer. Women may hate mammograms for obvious reasons, but mammograms increase a woman's chances of detecting breast cancer at an early stage. Early detection of breast cancer is more likely curable. The American Cancer Society recommends an annual screening mammogram for every woman 40 years or older. The risk of radiation from a mammogram is minimal,[1] compared to its benefit of saving lives. It is important to realize that our body is exposed to natural radiation every day. A screening mammography report describes details about the x-ray appearance of the breasts using the Breast Imaging Reporting and Data System (BIRADS)[2] as given in Table 3.1.

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[1] Radiation from a mammography is almost equivalent to seven weeks of radiation from natural sources which is minimal compared with radiation from a CT chest scan which is equivalent to two years of natural radiation, and a PET-CT scan radiation which is equivalent to 8 years of radiation from natural sources. Hence, radiation from mammogram (equivalent to 7 weeks of natural radiation) is minimal.

Ref: Radiation Dose in X-Ray and CT Exams:

http://radiologyinfo.org/en/info.cfm?pg=safety-xray

Natural radiation comes from the composition of the earth's crust. The main contributors are natural deposits of uranium, potassium, and thorium, which, in the process of natural decay, will release small amounts of ionizing radiation. Uranium and thorium are found essentially everywhere. Traces of these minerals are also found in building materials. Therefore, exposure to natural radiation can occur indoors as well as outdoors. Also, vegetables are typically cultivated in soil and ground water, which contain radioactive minerals.

Ref: Types and sources of radiation; Canadian Nuclear Safety Commission; http://nuclearsafety.gc.ca/eng/resources/radiation/introduction-to-radiation/types-and-sources-of-radiation.cfm

[2] Mammogram: National Breast Cancer Foundation, USA: http://national-breastcancer.org

Table 3.1 Mammogram results

Result	Interpretation
BIRAD 1	No abnormalities seen
BIRAD 2	One or more abnormalities seen, but clearly benign
BIRAD 3	One or more abnormalities seen, probably (not definitely) benign
BIRAD 4	One or more abnormalities seen, probably (not definitely), malignant
BIRAD 5	Abnormalities seen, malignant

Source: Mammogram: National Breast Cancer Foundation, USA: http://nationalbreastcancer.org

Diagnostic mammograms are used if a screening mammogram shows some abnormalities but suspicious results (e.g., BIRAD-4 reading). Diagnostic mammogram takes longer than screening mammogram because more x-rays are needed to obtain views of the breast from several angles.

Radiologists may perform additional studies such as an ultrasound of the breast,[3] computed tomography (CT) scan,[4] positron emission tomography (PET[5]) scan, or an magnetic resonance imaging (MRI)[6] to further evaluate a tumor, as these devices produce images with higher levels of resolution.

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[3] An ultrasound scan, also referred to as a sonogram, is a device that uses high-frequency sound waves to create an image of some part of the inside of the body, such as the breast, stomach, liver, heart, tendons, muscles, joints, and blood vessels.

[4] **CT scan**: CT uses special x-ray equipment to help detect a variety of diseases and conditions. CT scanning is fast, painless, noninvasive, and accurate. These images can be viewed on a computer monitor, printed on film, or transferred to a CD Unlike conventional x-rays, a CT scan provides detailed images of lungs, bones, soft tissues, and blood vessels.

[5] **PET scan** is a type of nuclear medicine imaging. Nuclear medicine procedures are able to pinpoint molecular activity within the body and thereby offer the potential to identify disease in its earliest stages as well as a patient's immediate response to therapeutic interventions.

[6] **MRI scan** is a radiology technique that uses magnetism, radio waves, and a computer to produce images of body structures. The image and resolution produced by MRI are quite detailed and can detect tiny changes in structures within the body. MRI is safer than CT scan as it does not use x-ray technology.

Sonogram

Ultrasonography plays an important role in the evaluation of breast cancer. Sonogram formed from ultrasound imaging is safe, and there is no risk of radiation since it does not use x-ray technology. Ultrasound could be the "first" diagnostic imaging method for young women with dense breast tissues, because mammograms of **dense breast tissues** are harder to interpret. Breast ultrasound results tend to fall into the following categories (Table 3.2).

A sonogram may be done to look at the size, location, and structure of breast tissues, distinguish fluid-filled cysts from solid tumors, guide the doctor during a needle aspiration or biopsy, assess the stage (how deeply a tumor has penetrated the wall of an organ), and detect abnormal blood flows through vessels (Doppler ultrasound), because blood flow is different in tumors than in normal tissues.

Table 3.2 Sonogram results

Category	Interpretations
1	Benign fibrous nodules (breast fibrocystic disease)
2	Indications of a "complex cyst"
3	Indications of suspicious lesion
4	Indications of lesion highly suggestive of cancer

Source: American Cancer Society: Mammograms and Other Breast Imaging Tests http://cancer.org/healthy/findcancerearly/examandtestdescriptions/mammogramsandotherbreastimagingprocedures/mammograms-and-other-breast-imaging-procedures-report

Breast Biopsies

Radiology tests are good at finding abnormal sites (abnormality in appearance, size, and location of the suspicious area) within the body; however, it is difficult to establish malignancy, just based on how it looks. A biopsy of the abnormal tissues is the only diagnostic procedure that can definitely determine if the suspicious area is cancerous or not.

A breast biopsy[7] is a procedure to remove tissue or sometimes fluid from the abnormal areas observed in sonograms/mammograms. The

[7] National Breast cancer Federation: Breast Biopsy; http://nationalbreastcancer.org/breast-cancer-biopsy

removed tissue/cells are examined under a microscope to diagnose breast cancer. A breast biopsy, if done under the guidance of a medical device (e.g., ultrasound) to detect the abnormal site, is called a guided biopsy. Breast biopsy can be classified under three types:

- **Fine needle aspiration** (FNA) may be performed to draw the fluid away, if the sonogram showed a fluid-filled cystic lump. When this procedure is over, the lump would contract since the fluid has been taken out. It is done with a thin needle and is an outpatient procedure. It does not need anesthesia and there are no stitches or incisions. It may diagnose but will not give information like estrogen receptor (ER), progesterone receptor (PR), or HER2 neu oncogene.
- **Core needle biopsy (**CNB) procedure uses a large core needle (hollow needle) to draw a sample tissue. A CNB is done under local anesthesia and gives more information than an FNA biopsy. The report for a core needle biopsy sample will include tumor type and the tumor's growth rate or grade. If cancer is found, the pathologist analyzes the tumor further for ER or PR. CNB leads to grading the carcinomas from Grade1 (well differentiated; relatively normal-looking cells that do not appear to be growing rapidly) to Grade 3 (poorly differentiated, lack of normal features, tend to grow and spread faster).
- **A surgical biopsy** (SB) removes all the abnormal area (instead of a sample) and a small amount of normal-looking tissue ("margin") around the abnormal area (to test if cancer has spread), and the tissue is sent for laboratory testing. An SB gives a more complete picture of the tumor than CNB, but is more invasive since it removes a large tissue from the breast. Sometimes a lumpectomy specimen is analyzed as a "frozen section specimen" while the patient is in the operation theater under anesthesia. If the pathologist reports this as a cancer, the surgeon proceeds with the planned surgery (e.g., a mastectomy or breast conservation).
- **Sentinel lymph node biopsy** (SLNB) is a procedure in which the sentinel lymph node (the node nearest to the malignant

tissue) is removed and examined to determine whether cancer cells are present. If results are negative, it indicates that cancer has not spread to nearby lymph nodes or other organs. If results are positive, it indicates that cancer may be present in other nearby lymph nodes and possibly other organs. This information helps a doctor to develop an appropriate treatment plan. SLNB may help some patients avoid more extensive lymph node surgery.

Hormone Receptor Tests (ER, PR)

Hormone receptor testing is generally recommended for those diagnosed with invasive breast cancer. Hormone receptor tests will determine whether the breast cancer is receptive to hormones or not.

Hormone receptors are specialized proteins located on the cell surface. Many breast cancer tumors are likely to contain a large number of hormone receptors for estrogen and progesterone hormones.[8] The hormone receptors get attached (bound) to the hormones and signal the cells to start growing and multiplying. If cancer cells start getting such signals, the hormone receptors will promote the growth of more and more cancer cells. Hence, it is necessary for oncologists to block the hormone receptors from getting attached to the hormones (estrogen and progesterone) to prevent cancer growth. Hormone therapy would respond well to breast cancers, which are positive for estrogen and/or progesterone. Knowing whether the cancer cells have hormone receptors is therefore valuable to decide the treatment plan.

HER2 Tests

Abnormal high levels of HER2 receptor (specialized protein) could drive breast cancer growth and speed. Drugs (Trastuzumab) that specifically

[8] Hormones like estrogen and progesterone are chemicals produced by glands in the body. Normally, these hormones help regulate body cycles, like menstruation. However, sometimes these same hormones can cause cancer to grow. Ref: Hormone Therapy; National Breast Cancer Foundation: http://nationalbreastcancer.org/breast-cancer-lab-tests

block HER2 to stop the growth of cancer cells are called HER2-targeted therapies. Testing for HER2 receptor status is usually done by immunohistochemistry (IHC) method and needs a biopsy specimen. A result of 0 or 1+ indicates there is no excess of HER2 protein in the cancerous cells and hence they are HER2 negative; HER2 level 3+ means the cells test positive for HER2 protein overexpression. Levels of HER2 at 2+ are borderline cases; it is advisable to go for additional test (such as fluorescence in situ hybridization [FISH][9] test) to decide the correct line of treatment.

Ki-67 Tests

Ki-67 is a cancer antigen found in growing and dividing cells. This characteristic makes Ki-67 a good tumor marker for the rate of tumor proliferation. The test is done on a sample of tumor tissue to help predict the outcome.

For breast cancer, outcome is considered to be favorable if Ki-67 <10%. Estimates of Ki-67 >20% would be considered high-grade tumors and would necessitate more intensive treatment such as chemotherapy. Evidence is building to recommend Ki-67 as a tumor marker in patients with newly diagnosed breast cancer.

PET-CT Scan

PET scanning is emerging as a very powerful technology for diagnostic imaging, especially with regard to staging and managing cancer treatment. Cancer cells are metabolically active because of their rapid rate of reproduction, and PET scanners provide produce functional information (metabolic activity) of tumors[10] or how active cells are in a tumor. However, they do not provide precise anatomical information. Hence, a PET

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[9] FISH is a test that "maps" the genetic material in a person's cells. FISH testing is done on breast cancer tissue removed during biopsy to see if the cells are HER2 positive.

[10] Metabolic activity is measured by the glucose intake by the cells. Malignant tumors are characterized by increased glucose metabolism compared with normal cells, as cancer cells are more active than normal cells.

scan image is superimposed on a CT scan[11] to provide both anatomical and metabolic information about the tissues and organ of interest. A hybrid technique combining PET and CT provides both metabolic and anatomical information about tumors.

Cancer Staging

Cancer staging[12] is the process to determine how much cancer is in the body, where it is located, and how much it has spread (Table 3.3). The most common and useful staging system for most types of cancers is

Table 3.3 Staging of cancer

Stage	Indications
0	Abnormal cells are still contained in the duct where they initially appeared
I	The tumor is less than 2 cm in diameter and small clusters of cancer cells may be found in the lymph nodes
II	The tumor is smaller than 2 cm in diameter and has spread to the lymph nodes in the armpit (see Figure 2.2) **OR** The tumor is between 2 and 5 cm in diameter but has not spread to the lymph nodes in the armpit Note: Stage II breast cancer is further classified as Stage II A and II B
III	The tumor maybe of any size, but - has spread either to the chest wall and/or the skin of the breast - has spread to at least 10 lymph nodes in the armpit, or the lymph nodes in the armpit are attached to each other or to other structures - has spread to lymph nodes near the sternum (breastbone) - has spread to lymph nodes below or above the clavicle (collarbone) Note: Stage III breast cancer is further classified as Stage III A. III B, and III C
IV	Cancer has spread to other organs of the body, most often the bones, lungs, liver, or brain. Such distant tumor deposits are called metastases

[11] CT and MRI scanners provide exquisite details about the size, shape, and other anatomical features of an abnormal mass.

[12] American Cancer Society; http://cancer.org/treatment/understandingyourdiagnosis/staging

the TNM[13] system suggested by the American Joint Committee on Cancer (AJCC) and the Union for International Cancer Control (UICC).

Cancer staging helps the team of oncologists to design an appropriate line of treatment, based on the severity of cancer and its spread.

Conclusion

In this chapter, we have discussed various steps and investigations to diagnose cancer and understand its characteristics to plan an evidence-based treatment. In the next chapter, we discuss treatment options such as surgery, chemotherapy, radiation therapy, and targeted therapy.

[13] T for tumor size, N for the number of lymph nodes with cancer, and M if cancer has metastasized or not.

CHAPTER 4

Breast Cancer: Medical Treatment

A Case Study: Anita

It was a cold wintry Sunday morning in December 2015. This was supposed to be a "healthy" season after almost six months of oppressive heat. Anita, a 26-year-old employee of an event management firm, was relaxing on her day off at home with her two-year-old daughter and her loving husband. Little did she know that life would soon take an ugly turn and she would embark on a journey, which would change her attitude toward life. A journey that, given a choice, no one would wish to undertake, but which would also help her discover her inner strength, make her a stronger woman, and give a new meaning to life.

While bathing, she noticed a lump in her left breast about the size of a peanut. Her maternal aunt had breast cancer and she was apparently cured of the disease. She immediately told her husband and they decided to see their family doctor the next morning. After examining her, the doctor asked her to see a surgeon. A sonography of the breast showed a 2 cm tumor on the outer side of the left breast. A fine needle aspiration in which a few cells were aspirated from the tumor with a needle confirmed that it was cancer. The surgeon advised a mastectomy. Anita was devastated and asked for some time to think it over.

After some preliminary inquiry, she decided to go to a cancer hospital in her city that had a multidisciplinary tumor board for decision making. She approached an oncologist there who examined her, went through all the investigation reports, and took her case to the tumor board. The tumor board comprised of a surgical oncologist, a medical oncologist, a radiation oncologist, a radiologist, a genetic counselor, and other specialists. Since she was very young, the board suggested

a confirmative tru-cut (removal of a small piece of the tumor). This would give a better picture of the pathology and would also help in further characterizing the tumor by looking for tumor markers of hormone receptors (estrogen receptor [ER] and progesterone receptor [PR]). Anita's biopsy showed her breast cells were ER positive (moderate) and PR positive (moderate), and human epidermal growth factor receptor (HER2 neu) gene expression was at a low level (1+). The findings from the biopsy recommended a breast-conserving surgery (BCS) to preserve her breast. The surgeon in the tumor board also felt that a mastectomy at this age would not be appropriate as she was very young and hence suggested a BCS. The medical oncologist suggested six cycles of standard chemotherapy and five years of hormonal therapy and radiation therapy. With this line of treatment, Anita could preserve her breast, so vital for her mental well-being. The board also suggested preserving her ova before chemotherapy, so she could have the option of a second child in future in case she developed infertility due to chemotherapy. The tumor board of the hospital conveyed to her its recommendations and what they perceived would be the best line of treatment for her. Anita and her family agreed with the recommendations of the tumor board.

Tumor Board

Multidisciplinary tumor boards are the norm in good cancer centers across the world. Decision making should not be in the hands of a single specialist, as the treatment of breast cancer, like many other cancers, involves a multidisciplinary approach. Hence, a multidisciplinary team should plan the treatment of each patient, so all the pros and cons are discussed before finalizing a treatment plan.[1] Tumor board discussions have reduced the mortality due to breast cancer (Kesson, and Allardice,

[1] ESMO 2015. "European Society for Medical Oncology; Primary Breast cancer: ESMO Clinical Practice Guidelines." *Ann Oncology* 26, Suppl 5, pp. v8–v30. http://esmo.org/Guidelines/Breast-Cancer/Primary-Breast-Cancer

et al. 2012).[2] Such tumor boards serve as a checkpoint for clinicians so that the most appropriate treatment is given to a patient by eliminating the "overlook" factor of an individual specialist.

Some of the important factors to be taken into account in designing treatment plans are given in Table 4.1.

Table 4.1 Some important factors for designing treatment plans

1	Age
2	Weight and height. The dose of chemotherapy depends on the body surface area calculated using the age and weight
3	Type of cancer, invasive or not
4	Size of the tumor; tumors larger than 5 cm are usually given chemotherapy before surgery (neoadjuvant chemotherapy)
5	Involvement of nearby areas such as skin of the breast, muscles below the breast, and so on. These are called "locally advanced breast cancers" or LABCs and are usually treated with neoadjuvant chemotherapy
6	Involvement of axillary nodes. As a rule, the more the nodes in the armpit, the more advanced the disease and the greater the need for neoadjuvant chemotherapy
7	Presence of distant spread of disease (metastases). Surgery is usually not indicated in these patients and the mainstay of treatment is chemotherapy with or without radiotherapy
8	Biological characteristic of the tumor—estrogen receptor (ER), progesterone receptor (PR), human epidermal growth factor receptor-2 (HER2 neu), and Ki-67
9	Estrogen receptor–positive tumors are dependent on estrogen hormones for growth and antiestrogen therapy controls the growth of these tumors to a large extent. Tumors positive for HER2/ neu are given anti-HER therapy for better results
10	Financial status and medical insurance are important issues that an oncologist considers before offering a therapy to a patient. For example, targeted therapies like trastuzumab are out of reach of most patients in India and hence treatment has to be tailored for such patients

[2] Kesson, E.M., G.M. Allardice,W.D. George, H.J.G. Burns, and D.S. Morrison. 2012. "Effects of Multidisciplinary Team Working on Breast Cancer Survival: Retrospective, Comparative, Interventional Cohort Study of 13722 Women. *BMJ,* p. 344. doi:https://doi.org/10.1136/bmj.e2718 (Published 26 April 2012) Cite this as: BMJ 2012;344:e2718

Treatment Options

Treatment options for breast cancer are given in Table 4.2.

Surgery

The type of surgery essentially depends on the tumor size. The patient has to decide if she wants to remove the whole breast or preserve the breast. In both circumstances, the nodes in the armpit or axilla have to be removed to check for the spread of cancer cells.

- Modified radical mastectomy (MRM). The whole breast along with fat below the skin is removed, and so are nodes in the axilla. As per standard recommendations, at least 10 nodes should be removed to check for evidence of cancer. After surgery, the pathologist reports the exact size of the tumor and number of nodes affected by cancer. This defines the exact stage of the cancer.
- Breast conservation surgery (BCS), also known as segmental mastectomy or breast preservation surgery. Usually, tumors less than or equal to 2 cm in diameter are advised a BCS procedure. However, if there are multiple small tumors less than 2 cm in size, then a total mastectomy is advised. Along

Table 4.2 Treatment options

Surgery	Primary surgery: a modified radical mastectomy (MRM) or a breast conservation surgery (BCS)
Chemotherapy	Chemotherapy, which could be neoadjuvant (before surgery), adjuvant (after surgery), or palliative (for metastatic disease)
Targeted Therapy	Targeted therapy in which special drugs, which are monoclonal antibodies, are used to destroy the cancer cells. Patients whose tumors show or express the HER2 neu marker are given drugs like trastuzumab or pertuzumab
Hormonal Therapy	Hormonal therapy, which are drugs that act on cells that express the estrogen receptor (ER) or progesterone receptor (PR)
Radiation Therapy	Radiation therapy wherein high-voltage radiation beams are given to the operative site and surrounding areas. Radiation may also be given as a palliative therapy for disease spreading to the bones to relieve pain or to prevent fractures

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with the tumor, nodes in the axilla are also removed to check for spread.

- A procedure called sentinel lymph node biopsy (SLNB) is done, especially in cases without palpable nodes. If the node is negative for cancer, then the axillary nodes are not removed during surgery.

Radiation Therapy

Use of modern linear accelerators is a well-established modality of treatment in most breast cancer patients. It may be given with a curative intent after complete surgery or with a palliative intent in metastatic disease.

Radiotherapy after total removal of the tumor or breast is essential because there may be some cancer cells remaining in the deeper tissues or nodes in the chest just behind the breastbone (sternum) or the nodes in the lower neck (supraclavicular). The duration of this radiation is for 20 to 25 days and the total dose delivered is about 40 to 45 Gray (Gy), which is the unit for radiation. It is given as daily fractions of small doses of radiation to reduce the chances of tissue damage and skin reactions due to radiation. The method used by the radiation oncologist is either 3D conformal or intensity-modulated radiation therapy (IMRT) or image-guided radiation therapy (IGRT). The cost of each varies and the radiation oncologist decides what is best for the patient. In addition to the standard calculated dose, sometimes a boost dose of 10 to 16 Gy is also given to the tumor bed (site of removed tumor).

When a BCS is done, as a thumb rule, all patients should receive curative radiation to the whole breast, axilla, and same side neck. On the other hand, when a total mastectomy with axillary clearance is done (MRM), radiation may not be given if the tumor is <5 cm and the axillary nodes are negative for cancer. In other circumstances, especially with positive axillary nodes and depending on the size of the tumor removed, radiation is strongly indicated.

Before radiation, a computed tomography (CT) scan is obtained of the chest to plan the size and shape of the radiation beam, and sometimes a “mask” or “jacket” is prepared to be worn by the patient to protect the

organs deep in the chest like the heart or lungs. This protective jacket is to be worn daily at the time of radiation. Among common radiation side effects is radiation dermatitis (inflammation of the skin), which can sometimes lead to peeling away of the superficial layer of the skin.

It should be remembered that only radiation therapy to the breast tumor, to avoid surgery or chemotherapy, will not be considered a standard or curative therapy,

Radiation given in the palliative setting is used to reduce bone pains when the cancer has spread to the bones. This is commonly given as fractions for 10 to 12 days only. This can be repeated for different bones when new areas develop cancer. It is also given for a short period when cancer has spread to the brain.

Chemotherapy

Breast cancer is a systemic disease, which means that cancer cells are found in the blood or distant parts of the body either at diagnosis or later, irrespective of the stage of the disease. Chemotherapy is a systemic therapy, which is usually given intravenously at a periodic interval (weekly, every 15 days, or once every 3 weeks) with the aim of attacking the cancer cells in the blood or any other distant part of the body (liver, bones, lungs, or brain). In most cases these are given intravenously, but some can be given orally too.

Most chemotherapy drugs act on the DNA of dividing cells and kill the cells. These drugs also destroy the DNA of normal dividing cells of the body found in bone marrow, skin, hair, mucosa (lining) of the gastrointestinal tract, and so on. Due to this, they have side effects on the bone marrow (suppression), mucosal lining (ulcers in mouth, loose motions), and hair follicles (hair loss).

Before any chemotherapy, there are mandatory investigations, which your oncologist will ask you to do apart from those done for diagnosis. Laboratory tests like hemogram (hemoglobin, white cell counts, platelet counts), liver function tests (bilirubin, serum glutamic pyruvic transaminase [SGPT]), and kidney function tests (creatinine, blood urea) are mandatory before each cycle. In addition, a two-dimensional (2D) echocardiography is done before chemotherapy to see the status of the heart as some chemotherapy drugs are toxic to the heart.

Chemotherapy is usually planned based on the tumor size, number of nodes in the axilla, stage of the cancer after surgery, presence or absence of metastases (spread), and receptor status (estrogen receptor [ER], progesterone receptor [PR], and HER). Chemotherapy is usually planned and administered by a medical oncologist.

Neoadjuvant Chemotherapy

Neoadjuvant chemotherapy (NCCN 2016)[3] is given before any surgery to reduce the tumor size and to destroy any cancer cells that may be in the blood circulation or may have spread to distant parts of the body (also known as micrometastasis). The drugs are given once every three weeks for three cycles or sometimes weekly for two to three months. After this, depending on the tumor shrinkage, surgery is done. Usually as a thumb rule, total mastectomy is done, but in some Western countries, breast conservation is also done.

There are some advantages in giving neoadjuvant chemotherapy, rather than going for surgery first. Shrinkage of tumor would indicate that the tumor is sensitive to a specific combination of chemotherapy drugs. If the tumor is removed first and then chemotherapy is planned, it is difficult to know if the tumor is sensitive to the combination of drugs being given and this may translate into poorer survival or early recurrences. Also, there is strong evidence now that if the tumor shrinks completely after neoadjuvant (known as complete response) chemotherapy, such patients have better long-term survival. Patients having a persistent disease in the breast after chemotherapy have a poorer survival.

Standard regimens used are FEC (5-fluorouracil + epirubicin + cyclophosphamide), AC regimen (doxorubicin + cyclophosphamide), TAC (docetaxel + doxorubicin + cyclophosphamide), TCH (docetaxel

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[3] NCCN 2016. National Comprehensive Cancer Network (NCCN) Guidelines; 2017. https://nccn.org/professionals/physician_gls/f_guidelines.asp
The National Comprehensive Cancer Network (NCCN®), a not-for-profit alliance of 27 of the world's leading cancer centers devoted to patient care, research, and education, is dedicated to improving the quality, effectiveness, and efficiency of cancer care so that patients can live better lives.

+ carboplatin + trastuzumab), or weekly paclitaxel. The choice of one regimen over another depends on various patient-related factors and local facilities available (hospital, trained nursing staff, availability of medicines).

Adjuvant Chemotherapy

Chemotherapy given after primary surgery is called adjuvant chemotherapy. It is usually given two to three weeks after surgery once the surgical wound heals and the pathology reports pathological reports are available. Again, the regimen would depend on various factors like age, pathological stage of tumor, receptor status (ER, PR, or HER), other medical conditions like diabetes mellitus and cardiac disease, and the financial condition of the patient. An adjuvant chemotherapy is given for six to eight cycles at three-weekly intervals. Adjuvant chemotherapy regimens may also include targeted drugs like trastuzumab. Many times, adjuvant chemotherapy is also followed by radiation therapy.

Palliative Chemotherapy

Palliative chemotherapy is given in the setting of metastatic disease, that is, stage IV disease. Again, this could be weekly or once every three weeks as planned by the oncologist. If the HER receptor is expressed in the tumor, anti-HER therapy like trastuzumab is also given. The selection of drugs for palliative therapy depends on the type of therapy received previously by the patient, the residual toxicity of previous chemotherapy, if any, and of course the financial condition. It is very important to understand that palliative chemotherapy may not extend life, but it could help in relieving symptoms like bony pains due to metastases. Good counseling and awareness of the possible benefits of palliative chemotherapy is essential. When there are bone metastases, an additional drug (zoledronic acid) is given once every three or four weeks to reduce the risk of fractures.

Targeted Therapy

Targeted therapies are drugs (oral or intravenous) that only act on some cancer cells depending on their characteristics. Only those cells and

tumors that have a specific surface marker are sensitive to that drug. For example, e*pidermal growth factor receptor* (EGFR) is a gene expressed in some lung cancers, and anti-EGFR therapy like gefitinib or erlotinib are oral drugs that act specifically on such tumors.

HER2 neu is a gene expressed in some breast tumors and such tumors are usually more aggressive and tend to recur earlier or spread faster. Anti-HER therapies have considerably improved the chances of survival and reduced the risk of recurrence. Trastuzumab is a drug that has dramatically changed the results of HER+ breast cancers (Gianni and Dafni 2011).[4] It can be given in a neoadjuvant setting along with other drugs or in adjuvant setting after surgery**.** It is also used in metastatic disease. The drug is given intravenously once every three to four weeks for 12 to 17 doses. Some oncologists use a weekly dose regimen for 12 doses and then continue once every three weeks. A one-year therapy is a standard recommendation for HER+ breast cancers (Slamon, Eiermann, et al. 2011).[5] One has to consider the toxicity of the drug, specially its cardiac toxicity, before starting. In most cases, the cardiac toxicity (decreased function) is temporary and reversible. During this therapy, cardiac function has to be regularly monitored with 2D echocardiography. The drug is continued for a total of one year (12 doses) as a single agent after all chemotherapy is completed.

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[4] Gianni, L., U. Dafni, R.D. Gelber, E. Azambuja, S. Muehlbauer, A. Goldhirsch, M. Untch, I. Smith, J. Baselga, C. Jackisch, D. Cameron, M. Mano, J.L. Pedrini, A. Veronesi, C. Mendiola, A. Pluzanska, V. Semiglazov, E. Vrdoljak, M.J. Eckart, Z. Shen, G. Skiadopoulos, M. Procter, K.I. Pritchard, M.J. Piccart-Gebhart, R. Bell, Herceptin Adjuvant (HERA) Trial Study Team. 2011. "Treatment with Trastuzumab for 1 Year After Adjuvant Chemotherapy in Patients with HER2-Positive Early Breast Cancer: A 4-Year Follow-Up of a Randomized Controlled Trial." *Lancet Oncology* 2, no. 3, pp. 236–44. doi:10.1016/S1470-2045(11)70033-X. Epub 2011 Feb 25

[5] Slamon, D., W. Eiermann, N. Robert, T. Pienkowski, M. Martin, M. Press, J. Mackey, J. Glaspy, A. Chan, M. Pawlicki, T. Pinter, V. Valero, M.-C. Liu, G. Sauter, G. von Minckwitz, F. Visco, V. Bee, M. Buyse, B. Bendahmane, I. Tabah-Fisch, M.-A. Lindsay, A. Riva, and J. Crown, for the Breast Cancer International Research Group. 2011. "Adjuvant Trastuzumab in HER2-Positive Breast Cancer**."** The New England Journal of Med 365, pp. 1273–1283. October 6, 2011. doi:10.1056/NEJMoa0910383

As it is expensive and has cardiac toxicity, proper selection of patients is essential. A patient should be able to take it for one year to get maximum benefit. One must also remember that given alone, targeted therapies have no role in the initial treatment of breast cancer; they are used alone only as maintenance therapy.

Another new drug is pertuzumab. This is given as part of a neoadjuvant regimen with the TCH regimen. It is extremely expensive, but because of the very encouraging results, it has recently been approved by the U.S. Food and Drug Administration (FDA). It is also used in the metastatic setting along with other agents.

Hormonal Therapy

Breast cancer to a large extent is a hormone-dependent cancer just like prostate cancer in males. The female hormones, estrogens, stimulate the growth of breast cancer cells. On biopsy, the tumors are analyzed for the expression of ER or PR and HER2 neu. Any degree of positivity reported by the pathologist is considered positive and treated with antiestrogen drugs like tamoxifen, anastrazole, letrozole, or exemestane. All these are oral drugs and are given once a day early morning on an empty stomach. Usually tamoxifen is given to premenopausal patients for at least 5 years, but based on recent research, it is recommended to be given for 10 years. It reduces the chances of recurrence by more than 20 percent. It can also be used in postmenopausal women. Sometimes, it is used for two to three years and then if the patient is postmenopausal, anastrazole or letrozole are given for a further two to three years. This is because tamoxifen-induced side effects increase after a period of two to three years after use.

Anastrazole, letrozole, and exemestane are a class of drugs known as aromatase inhibitors and they are given for five years and only in post-menopausal women. Usually, they are very safe, but patients can develop exhaustion and persistent muscle and/or joint pains. In some cases, these drugs have to be discontinued. Another long-term side effect of these drugs (specially the first two) is osteoporosis or decreased calcium content of bones with a tendency for fractures. Hence, before starting on these drugs, the oncologist will advise a bone density scan to see how

dense or strong the bones are. Patients on these drugs also need lifelong calcium and vitamin D3 supplements. Regular exercises are also essential for maintaining the strength of the bones.

Fulvestrant is an injectable antiestrogenic drug, which is given once a month in the buttocks. It is mainly used in advanced disease situations in postmenopausal women after failure of the oral drugs mentioned earlier.

CHAPTER 5

Breast Cancer: Physical Side Effects

Case Study: Journey of Prema (Part 3)

Soon after Prema's modified radical mastectomy (MRM) in May 2010, her surgical oncologist taught her a few arm exercises that would help her restore her left arm mobility. Soon after her surgery, Prema realized that she was unable to lift her arm, and bringing it over her head was impossible. Even lifting it parallel to the ground was excruciatingly painful. Looking in the mirror, she realized that the muscles in her armpit had become cordlike and extended all the way down her left arm to her palm. Her surgical oncologist talked about axillary web syndrome (AWS) or lymphatic cording. It took over six months of massage and exercises to get back mobility. Her arm started to feel stiff and heavy by January 2011. One month later, Prema and Prem were back to the medical oncologist. Prema was given antibiotics and painkillers, but the swelling continued. It took almost six months for the doctors to suspect lymphedema and Prema was advised to meet a physiotherapist. Six months later, a regular exercise regimen designed by her physiotherapist, yoga, and daily massage helped Prema to manage her lymphedema. If only she had been counseled about lymphedema earlier, she would not have lost four months trying to identify the reasons for her left arm swelling, pain, and stiffness. Another side effect was "chemo brain," which led to memory lapses, forgetfulness, and coordination problems.

Prem's constant surfing on the Internet revealed that more than 50 percent of cancer patients who underwent surgery suffer from lymphedema, and it could occur even many years later.

Common Physical Side Effects

Cancer and cancer treatments cause many common side effects such as pain, fatigue, skin and nail changes, nausea, changes in appetite, changing body image, loss of interest in sex, limitations in everyday physical functioning, and sleeping problems.[1] This is because of (a) injury to the surrounding skin and muscles during chemotherapy, radiation, and surgery, (b) removal of lymph nodes in the underarm area, or (c) nerve damage. The age and general health condition of the cancer patients, the type of treatment(s), and the amount or frequency of the treatment contribute to the severity of physical side effects. Side effects vary from person to person, even among those receiving the same treatment. Some people have very few side effects while others have many. In some patients, physical side effects continue for many years, though there is no sign of any disease. Sometimes physical symptoms might be manifestations of distress.[2]

- **Hair loss:** Chemotherapy and radiotherapy kill many cells in the body, which means they can also destroy hair roots. Some patients lose not only the hair on their head, but their eyelashes, eyebrows, and armpit hair according to the Mayo Clinic. Hair loss usually occurs about one to three weeks after the initial treatment. Hair loss is temporary, and hair will grow back 3 to 10 months after the treatment.
- **Skin and nail changes:** Cancer patients may experience constant and unpleasant itchiness. In some cases, their skin can become dry and red. These side effects are primarily due to

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[1] National Cancer Institute, NIH
https://cancer.gov/about-cancer/treatment/side-effects
American Cancer Society
www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/

[2] Psychosomatic disorders are a category of psychological concerns where emotional distress manifests itself in physical symptoms. Thus, if a complete medical examination does not reveal any biological basis, it is useful to explore if any psychological concerns might be overwhelming the individual and causing the physical reactions.

radiation therapies, which destroy skin cells. In some patients, skin rashes disappear only when the scars on the skin from radiotherapy disappear.

- **Limitations in activities of daily living:** The physical impairments and disabilities, as well as fatigue and pain experienced by patients with cancer often lead to an inability to perform the routine activities of daily living that most people take for granted.
- **Nausea:** Chemotherapy-induced nausea and vomiting (CINV) is a common side effect. Of late, the severity of CINV has come down with the administration of anti-nausea drugs before starting the chemotherapy session.
- **Sleeping problems:** Sleep is important to help the body cope with cancer treatment, including physical and emotional aspects. Insomnia, or trouble sleeping, is a common problem for patients with cancer. Symptoms of insomnia include difficulty falling asleep, multiple awakenings during night, early morning awakenings and being unable to get back to sleep, and so on.
- **Changes in appetite:** Cancer and its treatment are likely to cause changes in eating habits. Not eating properly could lead to weight loss and therefore weakness, fatigue, and even depression. Maintaining a good healthy diet is very important.
- **Pain:** Pain is a common side effect of cancer and cancer treatment. Pain may continue to be a problem even when there is no longer any sign of cancer. In a research study with women who had early-stage breast cancer surgery, about 47 percent reported experiencing recurring pain in different parts of their body even nearly two years after treatment.[3] Pain that

[3] Ref: at http://breastcancer.org/research-news/20091110b; BreastCancer.org (2009, 10 November).

continues three months beyond normal healing time qualifies as chronic pain (Bokhari and Sawatzky 2009).[4]

- **Fatigue:** Fatigue is the most frequently reported symptom of cancer and is identified as causing the greatest interference with patients' daily activities. Fatigue in cancer patients could persist even after rest and good sleep, since fatigue from cancer (Granz and Bower 2007)[5] is different from normal fatigue. Fatigue from cancer is the outcome of a complex combination of poorly understood physical and psychological effects of illness.
- **Body image:** Cancer treatments, such as surgery, chemotherapy, and radiotherapy, could cause changes in body image. They can change the way survivors feel about themselves (self-esteem) and make them feel self-conscious. Body image concerns are very sensitive for breast cancer survivors. Women who undergo lumpectomy have better body image compared to women who undergo mastectomy. Weight gain or obesity is another source for concern about body image among breast cancer patients.
- **Sexual health:** Sexual dysfunction in survivors is another major concern. Reasons could be varied such as stress, anxiety, depression, and poor body image. Some people lose interest in sex and feel very tired. As different people have different sexual needs and desires, it is impossible to describe the impact of cancer and its treatment on sex life. Low libido can also occur when cancer treatments disturb the normal hormone

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[4] (Bokhari and Sawatzky, 2009); Bokhari, F., and J.V. Sawatzky. 2009. "Chronic Neuropathic Pain in Women After Breast Cancer Treatment." *Pain Management Nursing* 10, no. 4, pp. 194–205.
For a brief understanding of chronic pain syndrome, watch the TED talk "What happens When You Have a Disease Doctors Can't Diagnose" by Jennifer Brea. The talk is available at http://blog.ted.com/the-story-of-a-baffling-illness-jen-brea-speaks-at-tedsummit/

[5] Ganz., P.A., and J.E. Bower. 2007. "Cancer related Fatigue: A Focus on Breast Cancer and Hodgkin's Disease Survivors." *Acta Oncologica 46*, pp. 474–79.

balance. Often low sex drive starts to improve after treatment is finished, but for some people it is ongoing.

Lymphedema

What Is Lymphedema?

Edema is swelling caused by fluid retention. Lymphedema is therefore the swelling caused by the retention of lymph fluid in our body. Lymph fluid is retained in the body when the lymph system is compromised/damaged. For example, surgical procedures such as radical mastectomy in breast cancer patients involve removing a few axillary lymph nodes in the armpit. The removal of lymph nodes blocks the flow of lymph from the arm, neck, breast, and chest regions, often leading to retention of lymph fluid, and causes breast cancer–related lymphedema (BCRL). Radiotherapy to the lymph nodes under the arm, which results in scarring and damaging the lymph system, also causes BCRL. Lymphedema could occur after surgery or radiation, months or even years later.[6]

1. Lymphedema from surgery: Lymph nodes, sentinel[7] and/or axillary lymph nodes (second-level nodes), are usually removed during a breast cancer surgery to determine whether cancer has spread beyond the breast. If a sentinel node biopsy (SNB) is done and no cancer cells are present, there is no need to remove any axillary nodes (under the armpit). The chances of lymphedema are considerably less in this case. If an SNB is performed and the sentinel nodes show the presence of cancer cells, any decision regarding the dissection of axillary nodes during a breast cancer surgery has to be taken by the surgeon. If SNB is not performed, the number of axillary nodes to

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[6] Brennan, M., and J. Weitz. 1992. "Lymphedema 30 Years after Radical Mastectomy." *Journal of Archives of Physical Medicine and Rehabilitation* 71, no. 1, February.

[7] Sentinel lymph node is defined as the first lymph node to which cancer cells are most likely to spread from a primary tumor. Sometimes, there can be more than one sentinel lymph node.

be dissected during a breast cancer surgery depends on the type of surgery performed.

2. Lymphedema from radiotherapy: Radiotherapy to the lymph nodes under the arm results in scarring and damaging the lymph system in this region, constricting the lymphatic vessels. This compromises the flow of lymph out of the breast, arm, and chest regions, leading to lymphedema. Radiotherapy also damages the cells within the nodes, especially if radiation is targeted to the axillary region to destroy malignant cells. Lymph node function is thus compromised, leading to lymphedema.

Lymphedema is an important consideration for clinicians who care for cancer patients because of its relatively high frequency and significant functional and quality-of-life implications for patients.[8] It is an independent indicator of decreased quality of life, irrespective of the socioeconomic profile of patients.

Management of Lymphedema

Management of lymphedema[9] deals with managing the complications arising from a compromised lymphatic system. The management of lymph edema[10] includes (1) preventing infections, especially skin infections, (2) diverting the collected lymph from the swollen limb to another lymphatic system, (3) exercise, and (4) diet control/weight management.

1. **Prevent infections:** Infection is the most common complication of lymphedema, as a compromised lymphatic system leads to decreased immune response to fight infection. Great care has to be taken to

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[8] National Cancer Institute; Patient Version: https://cancer.gov/about-cancer/treatment/side-effects/lymphedema/lymphedema-pdq

[9] Marco, C.M., R. Pillay, and C. Schoolheim. 2014. "The Management of Breast Cancer Related Lymphedema." *SAM Journal* 104, no. 5.

[10] Mei R Fu. 2014. "Breast Cancer-Related Lymphedema: Symptoms, Diagnosis, Risk Reduction, and Management. *World Journal of Clinical Oncology* 5, no. 3, pp. 241–47. http://ncbi.nlm.nih.gov/pmc/articles/PMC4127597/

prevent skin injuries in the affected limbs. This is because the lymphatic vessels, which lie just below the surface of the skin, fail to clear proteins conveying infection and thereby increase the risk of developing an infection, which could lead to increased swelling.[11] Redness, scratches, abrasions, or cuts are indications of skin infections. Keeping the swollen limb moisturized at all times could prevent skin infections. Skin care is thus very important to reduce the risk of developing skin infection.

2. **Divert the collected lymph:** Complete decongestive therapy (CDT) is a recommended gold standard for the management of lymphedema. The objective is to push the lymph collected in the swollen area (lymph collection due to a compromised lymphatic system) into an area where the lymphatic system is working properly.[12] CDT consists of the following procedures:

   - Manual lymphatic drainage
   - Simple lymphatic drainage
   - Compression/bandaging therapy
   - Pneumatic compression therapy

   Manual lymphatic drainage (MLD) is a gentle massage technique to the swollen area, which simulates the lymph vessels to contract frequently and channels the lymph fluid toward adjacent lymph vessels.[13] The massage should be gentle and mimic the natural lymphatic pulsations. The chest and neck areas are first massaged if the edema is in the arm, common for breast cancer patients. This opens

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[11] Skin Care for people with Lymph edema: LSN: The Lymphedema Support Network. file:///C:/Users/dell/Documents/Desktop/Skincare%20and%20Lymph%20edema.pdf

[12] Remember that the lymphatic system is an open system, unlike a blood circulatory system, which is closed. Hence if the lymphatic system in one part of our body is not working properly, it is possible to push the lymph collected in the compromised lymphatic system from one part of the body into another area of the body where the lymphatic system is working properly.

[13] MLD: http://cancerresearchuk.org/about-cancer/coping-with-cancer/coping-physically/lymphoedema/treating-lymphoedema/massage-mld for-lymphoedema#mE27i64WR5CrY17k.99

up the lymph vessels in these areas making them receptive to the lymph from the arm.

Simple lymphatic drainage (SLD) means self-massage.[14] In this technique, the swollen area is not massaged, as it is difficult to do oneself. Massaging areas near the swollen area could lead to freeing up space for the lymph node to drain into from the swollen areas. Only light pressure should be applied.

Compression/bandaging therapy[15] includes compression bandages and garments. Multilayered compression bandaging is generally applied soon after MLD. These garments help the muscles to pump in the area to be compressed so as to (1) mobilize the lymph fluid, (2) reduce the return of lymph to the affected area, and (3) prevent the progression of lymphedema.

Pneumatic compression therapy[16] (PCT) is another available alternative. Mechanical pneumatic pumps use electricity to inflate a sleeve, which produces external lymph compression. The sleeve is inflated and deflated on a timed cycle. These pumps can reduce swelling, but concerns exist over the displacement of fluids in other parts of the body at some future time.

3. **Regular exercises:** It is important to remember that the lymph system does not have its own pump like the heart. The lymph fluid therefore moves through action, exercise, and activity. Exercise is therefore necessary to keep lymph moving. Exercise massages the lymph vessels and moves extra lymphatic fluid out of the region.[17]

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[14] SLD for lymphedema: http://nhs.uk/ipgmedia/National/Macmillan%20Cancer%20Support/assets/SimplelymphaticdrainageSLDforlymphoedemaMC-S3pages.pdf

[15] Wanchai, A., J.M. Armer, B.R. Stewart, and B.B. Lasinski. 2016. "Breast Cancer Related Lymphedema: A Literature Review for Clinical Practice." *International Journal of Nursing science* 3, no. 2, pp. 202–207. http://sciencedirect.com/science/article/pii/S2352013215300673

[16] Nielsen, I., S. Gordon, and A. Selby. 2008. "Breast Cancer Related Lymphedema Risk Reduction Advice: A Challenge for Health Professionals." *Cancer Treatment Reviews* 34, pp. 621–628.

[17] How exercise helps lymphedema: cancerresearchuk.org/about-cancer/coping-with-cancer/coping-physically/lymphoedema/treating-lymphoedema/exercise-positioning;http://breastcancer.org/treatment/lymphedema/exercise

Combined with deep breathing, lymph movement within the lymph system is improved. Deep breathing before exercise helps to clear the lymphatic system in the chest area. This facilitates the flow of lymph from the arm edema into the chest. Deep breathing works by changing the pressure in the abdomen and chest. A plan should be devised by a trained therapist.

4. **Diet control:** Numerous studies have reported a statistically significant association between obesity and lymphedema.[18] A 20-year-old retrospective study showed that weight gain, since the treatment of breast cancer, is a stronger predictor of BCRL than being overweight at diagnosis. Extra weight puts an added stress on the already compromised lymphatic system.

   Weight loss should be achieved by following a healthy eating plan rather than through crash diets or by restricting certain food groups. Restricting certain food groups mean that patients are missing out on important nutrients. A healthy diet has plenty of fruits and vegetables and is low in saturated fat. A low-salt diet is recommended because high levels of sodium exert an osmotic pressure, which leads to fluid retention.

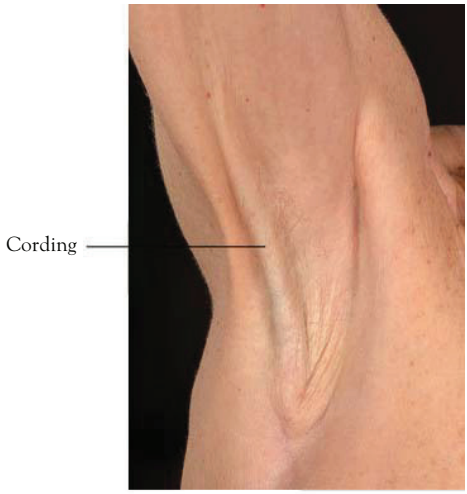
Axillary Web Syndrome (Cording)

Axillary web syndrome (AWS), also known as cording, is another side effect of breast cancer surgery. According to some researchers,19 cording is most likely caused by the removal of axillary (underarm) lymph nodes during breast cancer surgery, since surgery to the underarm traumatizes the connective tissues that encase nearby bundles of blood vessels, lymph vessels, and nerves. Scar tissue from surgery to the chest area to remove the cancer itself also can contribute to cording.

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[18] Rachel, D., and P. Neil. 2011. "Diet and BCRL: Facts and Fallacies on the Web." *Journal of Lymphedema* 6, pp. 36–42.

[19] Researchers are still studying what exactly makes cording happen. Very few studies have been done, and most have involved small numbers of patients. One study found that 20 percent of women went on to develop cording after sentinel lymph node biopsy, while 6 to 72 percent of the women developed cording after axillary lymph node dissection. Ref: Axillary Web Syndrome (Cording); http://breastcancer.org/treatment/side_effects/aws



Cancer Research UK

Figure 5.1 Cording

© Cancer Research UK [2002] All right reserved. Information taken 3rd May 2017

Cording typically occurs anywhere from several days to several weeks after surgery. These cords usually start near the site of any scarring in the underarm region or from near the chest wall and extend down the inner arm to the inside of the elbow (Figure 5.1). The cords tend to be painful and tight, making it difficult for the patient to lift her arm any higher than her shoulder or extend the elbow fully. This pain and limited range of motion can have a major impact on her day-to-day life.

Managing AWS

Those who develop cording are advised to consult a specialist in breast cancer rehabilitation. The natural reaction to the pain of cording is to avoid moving the arm and shoulder, which could lead to more tightness in the shoulder and chest area and thereby cause more serious problems with function and mobility. Moving and stretching under the guidance of an experienced therapist are the best ways to resolve the condition and stop the pain.

Fortunately, cording usually resolves itself for most people after a few therapy sessions, or at least within a few months. Usually cording is a one-time event that does not become a persistent problem.

Mondor's Disease

Mondor's disease is another side effect of breast cancer surgery or a core needle biopsy. This disease[20] is a rare condition caused by inflammation of a vein just under the skin of the breast or chest wall. It can affect any of the veins in the breast, but most commonly affects those on the outer side of the breast or under the nipple. What causes Mondor's disease is often unclear. However, it can be caused by vigorous exercise or an injury to the breast.

Chemo Brain

"Chemo fog" or mental fog" leading to cognitive dysfunctions is called chemo brain.[21] Cognitive dysfunctions include memory lapses[22] (even common information such as names and addresses), difficulty in concentrating, trouble coordinating, trouble multitasking, and severe tinnitus[23] of the ear. Many people with any form of cancer have been known to experience at least some of the symptoms already mentioned associated with chemo brain in the short term or long term. The term chemo brain was coined since it was thought that chemo brain was a consequence of chemotherapy. However, no conclusive evidence has yet been established,

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[20] Mondor Disease**:** http://emedicine.medscape.com/article/1087099-overview

[21] American Cancer Society; Chemo Brain; www.cancer.org/treatment/treatment-and-side-eefcts/physical-side-effects/changes-in0mood-or-thinking/chemo-brain.html

[22] Memory is of different types, depending on whether it is about specific incidents or remembering how to do things. Episodic memory refers to memory of specific information about particular events and experiences, such as remembering going to the theater the previous week. Procedural memory is memory of processes, of how to do things, such as how to drive a car. Semantic memory addresses the meaning of things and impersonal facts; it reminds us to use the pedestrian crossing and not step on to the road because of the knowledge that walking down the middle of the road in high traffic can lead to being run over. In chemo brain, the ability to draw upon these memory banks gets impaired or slows down, causing lapses in cognitive and motor activities.

[23] *Tinnitus* is a physical condition, experienced as noises or ringing in the *ears* or head when no such external physical noise is present.

and hence a new term *cancer brain* is emerging for cancer-induced cognitive dysfunctions.

Conclusion

"Just live with it" seems to be the general conclusion and advice given to people who are coping with BCRL. BCRL can have severe physical, practical, and psychological consequences for breast cancer survivors. It reduces quality of life through its physical, functional, emotional, and social consequences. However, the oft-repeated statement of breast cancer survivors is, "We were not warned or told/informed about BCRL." Patient awareness of BCRL and AWS would go a long way in the management of these side effects. This is more so since BCRL and AWS seem to be underdiagnosed and underrecognized in terms of their prevalence. Their impact on people suffering from them is even less studied and evaluated. Since BCRL is irreversible, management is the key. Awareness and prior knowledge would prepare the survivor to take the necessary steps/precautions soon after surgery.

CHAPTER 6

Breast Cancer: Psychosocial Side Effects

Case Study: Journey of Prema (Part 4)

Prema and Prem were informed/warned about physical side effects of the treatment by the oncologists and survivors. However, they did not hear even a whisper about the emotional side effects and changes in their social life. Nobody talked about it.

The first two chemo sessions went without any major side effects. After the third chemo, it was as if an unknown beast was unleashed within her. Prema was in a very dark place, overwhelmed by feelings of loneliness, helplessness, feelings of not being understood, and worst of all, not understanding her own behavior any more. Her mood swings were extreme and ranged from being upbeat one moment to being depressed five minutes later. By the sixth chemo, and through radiation, Prema realized, by pursuing a whole lot of self-education, that it was not she, but the cancer and the treatment that were responsible for her irrational behavior. If only, she felt, someone had told her that cancer treatment could destroy the strongest person, she might have dealt with it all very differently, from the start. Even after the chemo and radiotherapy sessions ended, she was often disoriented and confused. Joining a support group enabled Prema to vent and verbalize her feelings and draw strength and empathy from them.

While Prema continued to struggle through her situation, Prem was groping in the dark. He could not understand Prema's behavior. He wanted to believe that things would improve over time, but he too was getting tired, physically and emotionally.

Psychosocial Oncology

Recall the earlier description of cancer as a disease of the body and mind (Chapter 1, section "What Is Cancer?"). Cancer as a disease of the body has been discussed in detail in the earlier chapters. In this chapter, we discuss cancer as a disease of the mind.

"Psycho" means relating to the mind and the "social" part is about the relationships people have with family and the society at large (Canadian Association of Psychosocial Oncology [CAPO] 2012),[1] and hence this chapter deals with the psychosocial side effects of cancer. CAPO defines psychosocial oncology as

> a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer.

The field of psychosocial oncology is concerned with aspects of cancer that go beyond medical treatment and includes lifestyle, psychological, and *social* aspects of cancer so as to address the mind–body connection in cancer and its treatment. Though the field has been in existence for more than 25 years, it is only in the past decade that it has started receiving attention from researchers, doctors, and public health professionals. It is aimed at understanding the role of psychological processes in the emotional health and social life of cancer survivors.

Cancer and cancer treatments cause multiple side effects. The side effects could manifest as physical changes, psychological/emotional sufferings, and social life changes. The physical changes, by their very nature,

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[1] CAPO 2012. *The Emotional Facts of Life with Cancer: A Guide to Counseling and Support for Patients, Families and Friends*. 4th ed. Enbridge: Canadian Association of Psychosocial Oncology. www.capo.ca

are noticed (such as loss of a breast, swelling/edema, and fatigue).[2] Emotional sufferings are more insidious in nature (such as anger, depression, and fear) and thus often go unnoticed.[3] Social life changes, sometimes referred to as changes in the quality of life (such as stigma, interpersonal relations, and workplace identity), are experienced and felt.

Emotional Health

Our body responds to the way we think, feel, and act. When we are stressed, anxious, or upset, our body tells us that something is not right; our emotional health is out of balance. Poor emotional health weakens our body's immune system. A weakened immune system is prone to chronic diseases such as cancer.

Most cancer treatments, as well as cancer itself, can activate the immune system to release a special group of proteins called cytokines.[4] According to Dr. Miller,[5] "Research has shown that inflammatory cytokines can enter the brain and affect many of the brain circuits and chemicals that are involved in depression, anxiety, fatigue, and impairment in memory and concentration."

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[2] Physical side effects of breast cancer discussed in detail in Chapter 5 and hence not included here.

[3] Physical, emotional, and social changes are of equal importance. Being able to identify them would make it much easier to manage and cope with cancer treatment.

[4] Cytokines are a large group of proteins that are secreted by specific cells of our immune system. They are chemical messengers that signal to increase or decrease inflammation. Imbalance between proinflammatory and anti-inflammatory cytokines could have profound impact in depression.
Song, U., C. Halbreich, B.E. Han, L.H. Luo. 2009. "Imbalance between Pro- and Anti-Inflammatory Cytokines, and between Th1 and Th2 Cytokines In Depressed Patients." *Pharmacopsychiatry 42*, no. 5, pp. 182–88. doi:10.1055/s-0029-1202263. https://ncbi.nlm.nih.gov/pubmed/19724980

[5] Mood Changes Associated with Cancer Treatment—NCCN. https://nccn.org/patients/resources/life_with_cancer/.../mood_changes.aspx
Andrew H. Miller, MD, Director of Psychiatric Oncology at the Winship Cancer Institute at Emory University School of Medicine in Georgia, USA.

Some of the common symptoms of emotional health are:[6]

- Feeling overwhelmed
- Denial
- Loneliness
- Fear and worry
- Sadness
- Anger
- Stress and anxiety
- Depression

- **Overwhelmed:** When a person is first diagnosed with cancer, there is an immediate feeling of helplessness and life going out of control. The *C* word itself makes the persons concerned wonder if they are going to live, if they can afford the treatment, what life will be after the treatment, and what all the diagnostics and treatment mean. The person goes through the whole initial process in a daze and state of uncertainty.
- **Denial:** When a person is first told of the cancer diagnosis, there could be disbelief and an unwillingness to accept the prognosis. This is denial. They reason that they are vegetarians, nonsmokers, not obese, and so on, and therefore how could they get cancer? However, most often, by the time the treatment begins, people accept that they have cancer and move on with the treatment.
- **Loneliness:** People with cancer often feel distanced from others and therefore lonely. This could be due to the fact that cancer, along with its treatment, is such a strange beast. No one understands what a cancer patient goes through; it is difficult to understand unless it has been experienced. It is common knowledge that cancer treatment makes you feel like not talking with or meeting friends.

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[6] National Cancer Institute. https://cancer.gov/about-cancer/coping/feelings

- **Fear and worry:** Fear is an integral part of cancer prognosis. It could lead to fear and worry about dying, paying the bills, keeping the home running, retaining the job, the pain, and physical changes due to cancer and/or its treatment. Sometimes the fear or worry is the result of myths and rumors.
- **Sadness:** It is normal to feel sad during and after a serious illness. Many people with cancer feel sad. They feel a sense of loss of health and the life they had before they learned they had the disease. Sadness can bring on a sense of feeling tired and restless, and also loss of appetite. For most people these feelings lessen and go away over a period of time.
- **Anger:** People with cancer often feel angry. It's normal to ask, "Why me?" and be angry at the cancer. Anger is an emotion experienced by all people, triggered by an emotional hurt. These are feelings that one is unable to show, such as fear, anxiety, frustration, and helplessness. Anger is a valid reaction and there is no need to pretend that everything is fine. Extreme suppression of anger was the most commonly identified characteristic of 160 breast cancer patients who were given a detailed psychological interview and self-administered questionnaire in a study conducted by the King's College Hospital in London, as reported by the *Journal of Psychosomatic Research* (Greer and Morris 1975).[7]
- **Stress and anxiety:** It is normal to be stressed both during and after treatment. Stress could lead to anxiety and worry, which could prevent the body from healing. The common signs of stress could be headaches, muscle pain, feeling sick in the stomach, difficulty in concentration, sleeping too much or too little, and so on.
- **Depression:** If many of the symptoms mentioned in the preceding text persist over a few weeks, they could lead to

[7] Greer, S., T. Morris. 1975. "Psychological Attributes of Women Who Develop Breast Cancer: A Controlled Study." From the Faith Courtauld Unit for Human Studies in Cancer, King's College Hospital, London, S.E.5., UK; April 1975, Volume 19, Issue 2, Pages 147–53.

depression. Depression is not a disease, but rather a multifaceted sign of chronic immune system activation.[8] Every person has a different way of displaying emotional sufferings and therefore a different way of handling such situations. The chemical imbalance in the body caused by depression can trigger a number of symptoms: mentally, physically, emotionally, and behaviorally.[9] Emotional signs of depression include feeling emotionally numb, nervous or shaky, hopeless or helpless, short-tempered, moody, guilty or unworthy, as if life has no meaning, being unable to concentrate, crying for long periods of time or several times each day, focusing on worries and problems, feeling no interest in former hobbies and activities, and harboring thoughts about ways of hurting and killing oneself.

Social Life

While awareness about physical and psychological/emotional effects of cancer and its treatment is growing, the social impact of cancer is still not fully understood.[10] Cancer puts a strain on close and distant relationships. In the journey of a cancer survivor, their caregivers and members of the health care team are all co-travelers.

- **Interpersonal relationships:** Cancer affects the relationships of the patients with their families, friends, and caregivers. Maybe, close relatives expected to be with the cancer survi-

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[8] We all know that fever is not a disease; it is a sign of acute immune system activation, an indicator of the intensity of the war going on inside the body. In like fashion, depression is not a disease, but rather a multifaceted sign of chronic immune system activation, an indicator of disease severity.
smith, R.S. "Cytokines and Depression: How Your Immune System Causes Depression." http;//cytokines-and depression.com/chapter9.html

[9] https://depression-anxiety-stress-test.org/depression/symptoms-of-depression.html

[10] Cancer Network; Home of th-e journal of ONCOLOGY; www.cancernetwork.com/oncology-nursing/social-well-being-and-cancer-survivorship

vor throughout the cancer journey did not stay or vice versa. Some patients feel the need to withdraw from their social network during the cancer treatment, often resulting from the side effects of the treatment. Couples may have difficulty adjusting to role changes (Lange 2005).[11] According to Hirshaut and Pressman (2004),[12] it is necessary for the breast cancer survivor and her spouse to discuss each other's needs and wants, to maintain a good physical and intimate relationship, and to understand that it is natural if the patient wants to be left alone at certain times.

- **Financial burden:** A significant financial burden is part of the psychosocial cost of cancer for most survivors. Outpatient, multimodal treatment approaches, combined with inadequate reimbursement for cancer care and fear of recurrence (Alfano and Rowland 2006),[13] have increased the financial burden on patients and families. Fear of recurrence, one of the most universal and durable legacies of surviving cancer, is prevalent in cancer survivors across disease sites, and the prevalence ranges from 5 to 89 percent of survivors. Fear of recurrence has been ranked as the single largest concern of breast cancer survivors. Financial burden may trigger compromises in lifestyle, which leave the survivor often feeling frustrated and helpless, more so if insurance companies refuse to cover future cancer episodes or charge excessive premiums for coverage.
- **Workplace identity:** With the increasing number of cancer survivors, the importance of work ability, (re) employment, and social integration are emerging as critical areas, especially for breast cancer survivors. For women, employability after

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[11] Lange, V. 2005. *Be a Survivor: Your Guide to Breast Cancer Treatment*. Los Angeles, CA: Lange Productions.

[12] Hirshaut, Y., and P.I. Pressman. 2004. *Breast Cancer: The Complete Guide*. New York: Bantam Dell.

[13] Alfano, C.M., and J.H. Rowland. 2006. "Recovery Issues in Cancer Survivorship: A New Challenge for Supportive Care." *The Cancer Journal* 12, no. 5, September.

diagnosis and treatment are significant determinants of their sense of selfhood and independence. Some of the factors significantly associated with a greater likelihood of being employed or return to work are perceived employer accommodation, flexible working arrangements, counseling, gender issues, and fewer physical symptoms (Mehnert 2011).[14] Inability to relate to coworkers who have not experienced cancer and discrimination in the workplace (such as lower wages) are some of the concerns reported by cancer survivors (Mehnert et al. 2013).[15]

Caregiver Distress

Cancer affects the quality of the caregiver's life in a number of ways, often psychologically. The life of a caregiver (usually the spouse) is almost forgotten in the journey of a cancer patient. The caregiver's burden is complex and complicated by multiple competing priorities. Bottling up of feelings, personal neglect, potential uncertainty about the future, and helplessness in the face of caring for someone have been reported as stress factors of caregivers (Watson, Dunn et al. 2014).[16] As a result of unrelenting stress, they often experience negative psychological, behavioral, and physiological effects on their daily lives and health (Bevans 2012).[17]

No significant difference in the amount of distress was reported by patients and their caregivers in two separate studies based on the analysis

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[14] Mehner, A. 2011. "Employment and Work Related Issues in Cancer Survivors." *Critical Reviews in Oncology/Hematology* 77, no. 3, pp. 109–30.

[15] Mehnert, A., A. de Boer, M. Feuerstein. 2013. "Employment Challenges for Cancer Survivors." *Cancer* 119, pp. 2151–159.

[16] Watson, M., J. Dunn, and J.C. Holland. 2014. "Review of the History and Development in the Field of Psychosocial Oncology." *International review of psychiatry*, pp. 128–35. **Published online:** 25 Feb 2014

[17] Bevans, M.F. 2012. "Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients." *JAMA* 307, no. 4, pp. 398–403.

of a large number of patient–caregiver pairs (Hodges et al. 2005)[18] and (Hagedoorn et al. 2008).[19] The ultimate goal is for caregivers to be effective without compromising their health and well-being (Northouse et al. 2012).[20]

Psychosocial Counseling

In the context of emotional and social impact of cancer, it is possible to obtain professional help when needed. There is no need to cope alone. Going it alone could be taxing and traumatic. Professional help is available in the form of counselors (psychologists or psychiatrists) who are specially trained to help cancer patients. Counseling can also help in coping with issues other than the direct reactions to cancer and its treatment. These could include issues related to the family, practical issues, and personal issues. Most counselors use a three-stage process.[21] The types of counseling could be either of the following:

1. A counselor one-on-one with patients and their families
2. A peer support group led by a trained counselor

- **Exploration:** Wherein you begin by expressing the changes in your life due to cancer, your concerns and anxieties, and inability or ability to cope with the changes. This process helps you to identify and prioritize your issues and concerns.

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[18] Hodges, L.J., G.M. Humphris, G. Macfarlane. 2005. "A Meta-Analyticinvestigation of the Relationship between the Psychologicaldistress of Cancer Patients and their Carers." *Soc Sci Med,* 60, no. 1, pp. 1–12.

[19] Hagedoorn, M., R. Sanderman, H.N. Bolks, J. Tuinstra, and J.C. Coyne. 2008. "Distress Incouples Coping with Cancer: A Meta-Analysis and Critical Review of Role and Gender Effects." *Psychol Bull* 134, pp. 1–30.

[20] Northouse, L.L., M.C. Katapodi, A.M. Schafenacker, D. Weiss. 2012. "The Impact of Caregiving on the Psychological Well-being of Family Caregivers and Cancer Patients." *Seminars in Oncology Nursing* 28, no. 4, pp. 236–45.

[21] Counseling and Support for People with Cancer, Families and Friends; Department of Psychosocial Oncology, CancerCare Manitoba. www.cancercare.mb.ca

- **Understanding:** The next stage is to understand how you feel, think, and behave in relation to each concern/situation. Working through your behavior, thoughts, reactions, and feelings would help you arrive at a clearer understanding of what is working and what is not.
- **Action:** Once the issues are identified, understood, and prioritized, a course of action can be decided. Some examples of actions are (1) taking an active part in treatment decisions, and (2) learning coping mechanisms to handle the stress triggers, and so on.

Support Groups

Support groups can be formed in hospital settings, be organized by voluntary or social services organizations, or be set up through personal initiative. A support group comprising of survivors, a peer group, becomes the ear to listen with and shoulder to cry on during periods of aloneness and depression.[22] Support group members have no interest in a patient's past medical, emotional, or psychological history and are not there to judge and evaluate. These are women who have been there and done that, and that is all the qualification needed. Support groups provide a platform for nonjudgmental support from women who have themselves survived the journey and come out the stronger for it. In a sense, support groups are a means of empowering cancer patients. They enable the patients to gain emotional support from other women who have lived through and survived similar experiences. This can help reduce anxiety, fatigue, and confusion.

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[22] American Cancer Society. http://cancer.org/treatment/treatments-and-side-effects/physical-side-effects/changes-in-mood-or-thinking/chemo-brain.htm

CHAPTER 7

Breast Cancer: Complementary Therapies

Case Study: Journey of Prema (Part 5)

As the treatment progressed, it first took her body, then her mind, and only her soul remained. The doctors were doing an excellent job of treating Prema the cancer patient, but she was often left wondering, who/what would treat Prema the human being. She was rapidly transforming from being a very active, intelligent, vibrant, and good-humored multitasker to someone who was suffering physically, being in an unknown emotional space, slowly losing her language and quantitative skills. She seemed to be rapidly losing control of everything about her body and mind, and all this within a period of two months.

The two saving graces for Prema were her faith in God and her Yoga routine including Pranayams. Having been a practitioner of yoga and pranayam for many years, Prema practiced her pranayam even on days when she was so tired. On most days, she did as much of her yoga routine as she could. Emotionally too, whenever Prema felt herself going to a very dark place, three *omkars*, and she felt very relaxed.

A very dear friend, who was a *Reiki* practitioner, performed reiki on her, every day for three weeks, and it made a difference. It was as if slowly, all her past emotional baggage, hurt, and anger, that she was holding on to, was released. With yoga, pranayam, and reiki, a new Prema did emerge, calmer, at peace, positive, stronger, and more sorted. Thankfully, she found all the help she needed to heal and emerge a stronger and, in many ways, a better human being.

Prem, who did not have much faith in complementary therapies, started seeing the changes in Prema through yoga, pranayam, and reiki. He too slowly became a believer.

What Is Complementary Therapy?

A complementary therapy[1] is generally defined as any medical system, practice, or product that is NOT part of conventional medical care (a combination of surgery, chemotherapy, radiotherapy, and targeted therapy). It includes yoga and meditation, hypnotherapy (including guided imagery, relaxation, and visualization), acupressure, music therapy, Reiki (energy therapy), and more. It is important to note that complementary therapies are NOT alternatives to conventional medical treatments. On the contrary, these approaches help in more effective and holistic management of the medical treatment, its side effects, and the recovery process.

A Holistic View of the Human Body

For integrated management of any disease, it is important to understand the holistic perspective of the human body. The human body consists of five layers (*panch kosha*[2,3]), namely, physical body (*annamaya kosha*), energy layer (*pranamaya kosha*), mind/emotional layer (*manomaya kosha*), intellectual layer (*vijnamamaya kosha*), and bliss layer (*anandamaya kosha*) (see Figure 7.1). These five layers are not separate but are merged with each other, just like the ingredients in a curry.[4]

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[1] National Center for Complementary and Integrative Health; National Institute of Health; USA; https://nccih.nih.gov/

If a nonmainstream practice (e.g., yoga) is used together with conventional medicine, it's considered "complementary." If a nonmainstream practice is used in place of conventional medicine, it's considered "alternative." If conventional and complementary approaches are used together in a coordinated way, it is also considered "integrative medicine." For the purpose of the book, we will use the word "complementary therapy."

[2] In Sanskrit language, panch means five; koshas mean sheaths (or layers).

[3] For further details, refer to "Yoga for Cancer" by Dr Nagarathna R, Dr. Nagendra H R published by Swami Vivekananda Yoga Prakashana, India (www.vyasa.org)

[4] A curry consists of salt, turmeric, lentils, and so on, but these ingredients are all merged in the curry and cannot be separated.

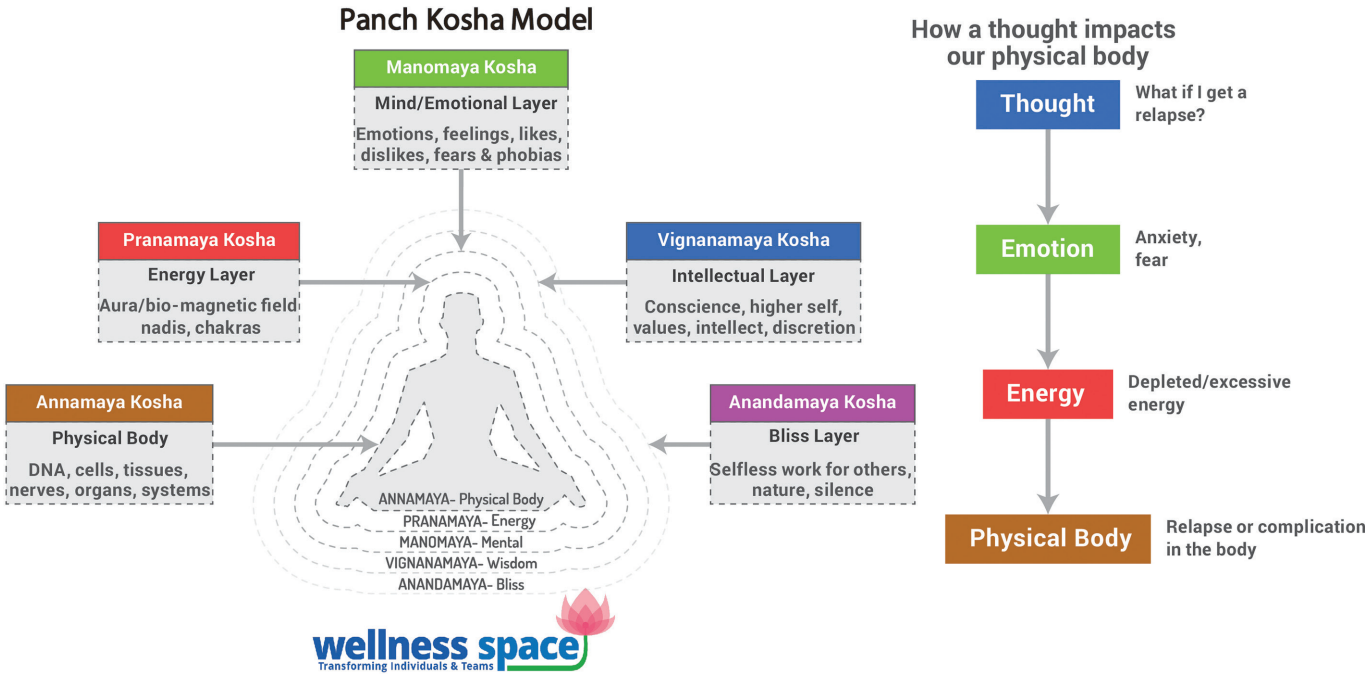


Figure 7.1 Pancha Kosha model

Note: A holistic view of the human existence and how a thought impacts our physical body.

Physical Body (Annamaya Kosha)

The physical body, as we all know, consists of cells, tissues, organs, and systems (respiratory system, cardiovascular system, etc.). All the conventional medical approaches in cancer treatment (surgery, chemotherapy, radiotherapy) work on the physical body, causing pain, scars, fatigue, and so on. It is therefore necessary to maintain the body and keep it healthy. This can be achieved by eating good wholesome organic and natural food and pursuing an active healthy lifestyle. Yoga postures, Sun salutations, brisk walking, working out at the gym, swimming, sports, and other physical exercises nourish the physical body and keep it fit.

Energy Layer (Pranamaya Kosha)

This layer carries energy to various parts of our body, through a complex network of energy circuits, called *naadis*. There are seven major junctions (*chakras*) where the energy circuits meet (Potter 2013).[5] Any imbalance in the energy (high or low) affects the endocrine glands associated with the chakras, which in turn block the energy circuits. It is therefore necessary to replenish or release the blocked energy, and this can be achieved through yogic breathing techniques (pranayam), *kriyas*,[6] Reiki,[7] acupressure,[8] or other therapies that work on energy. Fresh wholesome food and moderate exposure to sunlight would also increase our energy.

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[5] Porter, P.J. 2013. "Energy Therapies in Advanced Practice Oncology: An Evidence-based Practice Approach." *The Journal of Advanced Practitioner in Oncology*. Canada, May 2013.

[6] Cleansing practices in yoga like jal neti (nasal cleaning), kapalbhati (sinus and nostril cleaning using rapid breathing), kunjal (cleaning stomach with saline water), laghu shankh prakshalana (bowels cleaning), and so on.

[7] Reiki is a Japanese form of therapy that is delivered through the hands. Reiki means "universal life energy."

[8] Acupressure is based on the concept of life energy, which flows through "meridians" in the body. In treatment, physical pressure is applied to acupuncture points with the aim of clearing blockages in these meridians. Pressure may be applied by hand, by elbow, or with various devices.

Mind/Emotional Layer (Manomaya Kosha)

This is the mind layer, composed of *manas*, meaning *mind*. In fact, the mind layer[9] consists of two parts, namely, the conscious mind and the subconscious mind.

Over a period of time, negative emotions such as fear, anxiety, and so on, cause imbalance in the mind layer and permeate into the energy layer causing energy imbalances (either very low energy or heightened energy and chronic stress). The imbalance in the energetic field, if continued over a period of time, eventually ends up as disease in the organ or gland associated with that energy center (chakra). This is the reason why working only on the physical body does not really "cure" or "remove" the imbalance that originated in either the energy or the mind layer. Meditation, psychotherapy, hypnotherapy (including imagery relaxation techniques),[10] regression

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[9] For the purpose of this book, we focus only on conscious and subconscious mind and keep the discussions simple. However, experts (Sigmund Freud, *yoga nidra* practitioners) also talked about the unconscious mind.

The logical, analytical, and judgmental conscious mind (about 10 percent) is our processor that we use for all our daily activities. If you consider the iceberg analogy, this is equivalent to the tip of the iceberg.

The subconscious mind (the balance 90 percent) is similar to the part of the iceberg that stays inside water. It stores everything we have experienced—memories, habits, and belief systems. It is home to all emotions including fear, phobias, anxiety, and so on. The subconscious mind is significantly more powerful than the conscious mind, and hence it impacts the body. Therefore, it becomes vital to work with the subconscious mind for effective healing and recovery. Guided imagery, hypnotherapy, and yoga nidra work on the subconscious mind to erase all negative emotions from the mind.

[10] University of Maryland Medical Center website (http://umm.edu/health/medical/altmed/treatment/hypnotherapy)

The term hypnosis comes from the Greek word hypnos, meaning sleep. Hypnotherapists use exercises that bring about deep relaxation and an altered state of consciousness, also known as a trance. A person in a deeply focused state is unusually responsive to an idea or image. This does not mean that a hypnotherapist can control the person's mind and free will. On the contrary, hypnosis can actually teach people how to master their own states of awareness.

therapy, counseling, and yoga nidra[11] work on this layer. The mind layer can be nourished by positive thoughts, forgiveness, and courage.

Intellectual Layer (Vijnanamaya Kosha)

This is the layer of awareness, understanding, and reasoning. The mind layer lays the groundwork for reaching the intellectual layer since the mind needs to be in balance to correctly interpret what is happening in the body. People who connect with this layer have the wisdom/intellect to understand how to heal their mind and body (e.g., imagine you are trying to catch a train and are repeatedly blocked by students who are slow to move away from your path. You continue to get irritated and angry but when you suddenly realize that these students are all blind, the anger immediately subsides and could be replaced by the positive emotion of compassion. This is the power of the intellect or higher level of understanding). This layer is very subtle (compared to the mind layer), and so many people are unaware of its existence. A balanced intellectual layer could overcome the emotional side effects (from cancer and cancer treatments) and help us move forward in life with objectivity. This layer can be nourished by spiritual discourses, reading of scriptures, leading a disciplined yogic lifestyle, and taking control of situations, as well as understanding the self and the world around.

Bliss Layer (Anandamaya Kosha)

This is the layer of pure and spiritual happiness. This is the happiness when all the other four layers are balanced. Describing anandamaya (bliss layer) is very difficult. Anandamaya can be experienced when one is completely immersed in what one is doing, for example, work, prayers, and enjoying nature. This is what all complementary therapies eventually seek to achieve. A person in this layer is in a state of enlightenment or *nirvana*

[11] For further details, refer to Yoga Nidra by Swami Satyananda Saraswati (Bihar School of Yoga Publication).

and is immersed in compassion and joy. A human being is in perfect health when he or she is established in anandamaya kosha.[12]

Complementary Therapies

- **Yoga and meditation:** It is important to understand here that yoga is not just a series of complicated postures but also includes practices covering all our layers of existence including meditation that works on the mind layer and the energy layer. For example, nearly three out of four cancer patients face cognitive impairment (discussed in Chapter 6 where the person has trouble processing information, and this includes mental tasks related to attention span, thinking, and short-term memory) and for many, it continues for months after the treatment.[13] To address cognitive impairment, the solution must work on all five layers of existence and must strive to restore the balance of each layer. This is where an integrated approach that includes yoga and meditation can help. The recommendation, based on the evidence,[14] is presented in the following text.

  Meditation practices help in improving cognitive functions and psychological health for cancer patients and the survivors. Cognitive function is becoming increasingly critical as an aspect of quality of life (QoL) in cancer patients and

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[12] Easwaran, E. 1973. Three Upanishads: Isha, Mandukya, and Shvetashvatara. 1st ed. California: Nilgiri Press.

[13] http://cancer.net/navigating-cancer-care/side-effects/attention-thinking-or-memory-problems

[14] Clinical Practice Guidelines on the Use of Integrative Therapies as Supportive Care in Patients Treated for Breast Cancer, Heather Greenlee et al. Published by Oxford University Press. All rights reserved.
Holger CramerEmail author, Silke Lange, Petra Klose, Anna Paul and Gustav Dobos, Yoga for breast cancer patients and survivors: a systematic review and meta-analysis, BMC Cancer201212:412

survivors.[15] In order to achieve the same objective, there are many different types of meditations available to choose from. Mindfulness-based stress relaxation (MBSR) practice that combines yoga practices, sitting and walking meditation, rotation of consciousness, and so on, is one such practice that has demonstrated significant benefits on QoL and psychological health.[16] Meditation also has demonstrated benefit for anxiety and stress, mood disorder, and depression. If unable to reach out to an MBSR practitioner, explore available meditation practitioners and identify one practice that works well. It is best to practice meditation at the same time and place and it can be continued during chemotherapy and/or radiotherapy.

Integrated yoga practices (e.g., postures and joint loosening work on the physical body and energy layer, deep relaxation works on the energy and the mind layer) will definitely help in improving the psychological health (anxiety and stress, mood disorder, and depression), especially during breast cancer treatment.[17] Recommended sequence (practiced at www.svyasa.org based on their research) includes about 15 minutes of joint-loosening practices and 20 minutes of specific postures, followed by about 15 minutes of deep relaxation techniques. Yoga nidra[18] (the yogic art of relaxation works on the mind and the energy layer, while providing deep rest to the physical body) helps patients reach a state between sleep and wakefulness, wherein the healing is facilitated.

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[15] Biegler KA1, Chaoul MA, Cohen L., Cancer, cognitive impairment, and meditation. Acta Oncol. 2009;48(1):18–26. doi: 10.1080/02841860802415535.

[16] Cramer, H., R. Lauche, A. Paul, and G. Dobos. 2012. "Mindfulness-Based Stress Reduction for Breast Cancer—A Systematic Review and Meta-Analysis." *Curr Oncol* 19, no. 5, pp. e343–e352.

[17] Cramer, H., S. Lange, P. Klose, A. Paul, and G. Dobos. 2012. "Yoga for Breast Cancer Patients and Survivors: A Systematic Review and Meta-Analysis." *BMC Cancer* 12, no. 1, p. 412.

[18] Further research is being conducted in this area. Click to download https://mdanderson.org/publications/cancer-newsline/spring-2015/sleep-yoga-between-relaxation-and-meditation.html

It is best to seek guidance from an experienced yoga therapist to integrate postures, breathing practices, relaxation, and meditation.

- **Hypnotherapy:**[19] Hypnotherapy is a therapy that uses hypnosis.[20] You are in a trancelike state where your physical body is deeply relaxed but your mind is active. All people go into such states of mind (layer) naturally in daily life, for example, when daydreaming or concentrating deeply on something. A hypnotherapist can use various methods to put the person into a trance state. The person stays in control at all times and may feel heavy or light but remain relaxed. When the person is in this relaxed state, the hypnotherapist suggests things that might help the person to change the behavior or relieve symptoms. Current research[21] in this area suggests that hypnotherapy can reduce stress and help in the management of pain, distress, fatigue, and nausea associated with breast cancer surgery.

  Overall, hypnosis can be useful in the management of breast cancer–related symptoms (during biopsy or surgery or for women with metastatic breast cancer and the survivors). It is recommended to seek help from a certified hypnotherapist and integrate relaxation and guided imagery (visualization) during the sessions. Studies also indicate that incorporating the session findings into self-hypnosis can also help for ongoing practice. Hypnotherapy balances the mind/emotions (the mind layer), facilitates the healing at the intellectual layer, and influences the energy layer in the process.

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[19] Hypnotherapy includes relaxation, guided imagery, and self-hypnosis.

[20] www.cancerresearchuk.org describes many complementary therapies including hypnotherapy.

[21] Cramer, H et al. 2015. "Hypnosis in Breast Cancer Care: A Systematic Review of Randomized Controlled Trials." Integr Cancer Ther 14, no. 1, pp. 5–15. doi:10.1177/1534735414550035. Epub 2014 Sep 18.

- **Acupressure:** Nausea and, to a lesser extent, vomiting (CINV[22]) remain significant clinical problems after the administration of chemotherapy, with up to 60 percent of patients reporting nausea despite use of antiemetics.[23] For such symptoms, acupressure has demonstrated significant benefits to the patients. Acupressure is a safe and effective tool and must be offered to women undergoing chemotherapy for breast cancer.[24]
- **Music therapy:** One of the main reasons people with cancer use music therapy is because it makes them feel good.[25] Calming and relaxing effects of one's favorite piece of music are well known. It can help people to cope with side effects such as pain, anxiety, depression, and sickness by working on the mind/emotion layer. Music therapy sessions usually last between 30 and 60 minutes. The therapist may encourage the person to play or listen to music at home between sessions. Depending on the situation, the person may have regular therapy for weeks or months. One can consult the music therapist privately or take part in group music therapy sessions. Suggested practices in this area can also include the use of any form of soothing sound (e.g., Singing Bowls[26]) and music to soothe the nerves and induce relaxation, which promotes homeostasis and recovery.

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[22] Chemotherapy-induced nausea and vomiting

[23] https://google.co.in/search?q=p6+acupressure+breast+cancer&oq=p6+acupressure+breast+cancer&aqs=chrome..69i57j69i60j69i65j69i61l3.5249j0j4&sourceid=chrome&ie=UTF-8

[24] https://researchgate.net/profile/Hope_Rugo/publication/6116292_Acupressure_For_Chemotherapy-Induced_Nausea_And_Vomiting_A_Randomized_Clinical_Trial/links/0fcfd50b713b254b71000000.pdf

[25] Further details are available on www.cancerresearchuk.org

[26] This 2016 study indicated that Tibetan Bowls decrease anxiety, arousal, involuntary mental activity and stress in metastatic cancer patients. https://researchgate.net/publication/304107353_Feasibility_of_a_trial_with_Tibetan_Singing_Bowls_and_suggested_benefits_in_metastatic_cancer_patients_A_pilot_study_in_an_Italian_Oncology_Unit

- **Energy therapies:**[27] Therapeutic touch, healing touch, and Reiki are common energy therapies offered by providers in the health care setting. Recent findings report a positive benefit in the realms of QoL and health function for women receiving radiation treatment; fatigue and QoL for patients who have completed chemotherapy; pain and fatigue in women receiving chemotherapy; and improved mood and innate immune response preservation.

  Patients treated with hands-on touch while receiving chemotherapy demonstrated improved comfort and well-being from actual as well as placebo treatments. One such therapy is Reiki, a Japanese form of therapy that is delivered through the hands. Reiki means "universal life energy." Reiki attempts to balance the flow of the energy layer and stimulate the body's healing abilities. While research studies in Reiki and breast cancer are limited, Reiki may be able to bring about feelings of deep relaxation, warmth, or sleepiness and increased well-being.

Table 7.1 summarizes the discussion on complementary therapies.

Integrated Approach

Integrated approach is the practice of complementing the core medical treatment with complementary therapies. The integrated approach of medical treatment (to kill cancer cells and thereby minimize the chances of their recurrence) AND complementary therapies to restore balance in the body and mind, is the way to improve the QoL of cancer survivors. It helps to address the patient and the person, the human being.

[27] J Adv Pract Oncol. 2013 May-Jun; 4(3): 139–151. Published online 2013 May 1.

Download From: AghaLibrary.com

Table 7.1 Evidence-based recommendations

Side effects	Description	Complementary therapy	Comments
Anxiety/stress	Restlessness, nervous, worry, concern, unease about uncertain outcome	Yoga and meditation (MBSR or other), stress management practices	Reduces long-term anxiety/stress during and after chemo and radiation therapy. Can help in managing energy and emotions for patient, survivor, and caregiver
Depression/mood disorder	Lower energy level, less motivation, heightened perception of pain, withdrawal from social life	Yoga and meditation (MBSR or other) relaxation, hypnotherapy (including relaxation and guided imagery)	Improves mood and depression during radiation therapy and after treatment Can help in managing energy and emotions for patient, survivor, and caregiver
Sleeplessness	Less sleep, more movement (tossing around)	Yoga (including yoga nidra) Stress management	Any practice that reduces stress should help
Cognitive impairment and impact on quality of life	State of mental and physical health, material happiness, living conditions, work environment. cognitive impairment (includes mental tasks related to attention span, thinking, and short-term memory)	Meditation (MBSR or other) Reflexology Stress management	To improve quality of life and manage cognitive impairment
CINV	Chemotherapy-induced nausea and vomiting	Hypnotherapy (including relaxation and guided imagery) Acupressure Antiemetic medicines	To improve quality of life
Fatigue	Not enough energy, tired all the time	Acupuncture	Posttreatment acupuncture to manage fatigue

Abbreviation: MBSR, mindfulness-based stress relaxation.

CHAPTER 8

Patient-Centric Cancer Care

Case Studies

Case 1: When I started practicing in the United States in the late 1970s, I used to have 80 to 100 patients a day. About 40 to 50 were outpatients and 50 to 60 were inpatients. I would start my consultation by 9:30 a.m. After lunch, I would do my radiation sessions. I was very popular, and people within a 100-mile radius would come to my clinic. One day, a new doctor at my clinic asked one of my patients: "What is so special about Dr. AJ?" My patient replied, "You know he's very busy, but he treats me like I'm the only patient."

Case 2: Phyllis was 44 years old. She had breast cancer with bone metastasis. I still remember her room: 474. I went there and started talking to her after reviewing her medical records. As I was speaking, she looked at me and said, "You mean I'm not terminal?" She went on to tell me that she worked at GE, she loved bicycling, her origins were from Ireland, and it was her desire to work until she was 62, then retire, and visit her homeland. I heard everything she said, and told her, "Look Phyllis, you're not terminal. We can lay out a plan, and you can go back to work." We created a personal profile for her, which included "chemo holidays." During these "holidays," which lasted two to three weeks, we kept in touch with her and she felt comfortable because she knew we were monitoring her condition. She went to Ireland and got to fulfill all her dreams. After seven years, I got a call saying Phyllis was very sick and she had some problems in her lungs. I went to her home because she really wanted to see me. She was coughing profusely. I told her, "Phyllis, tomorrow is Monday, we'll try a new drug," but she said, "No, I wanted to thank you. In 7 years, I have achieved everything in life."

Dr. B.S. Ajaikumar, Chairman & CEO, HCG Enterprises Ltd., largest cancer care network in South Asia.

Cancer Care Quality: Patient Satisfaction

Cancer is an enigma and a very heterogeneous group of diseases. As we begin to understand this phenomenon of cancer, the whole approach to cancer treatment is changing. Significant developments in medical oncology, which increased the chances of patient survival, led to doctor-centered treatment plans where the patients were informed of their treatment after the doctors made their decision. The distance between the patients and their doctors stared widening. Unfortunately, doctor-centered treatment plans failed to achieve patient satisfaction, which is a critical determinant of the quality of life of cancer survivors.

The Institute of Medicine (IOM 1999) report[1] "Ensuring Quality Cancer Care" argued for evaluating the quality of care by looking at the survival period of cancer patients and the quality of life during that period. This report stressed the importance of cancer care quality. Following the report, the Department of Health and Human Services constituted a Cancer Care Quality Committee under the National Cancer Institute aimed at improving the quality of cancer care.[2] The report from IOM

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[1] IOM 1999. Ensuring Quality Cancer Care; Maria Hewitt and Joseph V. Simone, Editors; National Cancer Policy Board, Institute of Medicine and National Research Council; ISBN: 0-309-51879-2, 256 pages, 8.5 x 11, (1999); Ensuring Quality Cancer Care http://nap.edu/catalog/6467.html
This report highlighted the difference between the quality of cancer care in the United States and the care that cancer patients should get: "Quality of care means providing patients with appropriate services in a technically competent manner, with good communication, shared decision making and cultural sensitivity." In the case of breast cancer, the report pointed out problems with underuse of mammography for early cancer detection, lack of adherence to standards of diagnosis (such as biopsies and pathology studies), inadequate patient counseling for treatment options, and so on.

[2] The IOM Quality Initiative: A Progress Report at Year Six; Shaping the Future; IOM Newsletter; Volume I, Number I, Winter 2002; http://health.usf.edu/medicine/educationalaffairs/pace_files/IOM%20Quality%20Initiative.pdf

(2013)[3] on delivering high-quality cancer care raised several issues on the coordination of cancer care across multiple service providers.

Literature reviews of 25 published articles over the period 1996 through 2009 (Colosia, Peltz, et al. 2011)[4] and 15 published articles over the period 2009 through 2013 (Hess and Pohl 2013)[5] highlighted the lack of required comprehensive information to enable patients and families to take an active part in making decisions for treatment and care plans (Table 8.1). A recent article (Harolds 2015)[6] has reiterated some continuing major problems with cancer care quality, especially in meeting the perceptions of patients and families.

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[3] IOM 2013. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis; Committee on Improving the Quality of Cancer Care, Institute of Medicine; The National Academic Press: https://nap.edu/catalog/18359/delivering-high-quality-cancer-care-charting-a-new-course-for "Patients and their families often play the role of principal communicator as they visit one cancer treatment specialist after another, conveying the recommendations to subsequent consultants in a serial fashion. Coordination of complex cancer care, using a common electronic health record, with treating specialists who jointly discuss the patient's case and then confer with the patient about their recommendations, is the exception and not the rule. Receipt of psychosocial support at the time of diagnosis and during treatment is also rare, as these 'high-touch' services are seldom compensated through health insurance and are usually supported through ad hoc philanthropic funding rather than institutional or clinical practice resources."

[4] Colosia AD1, Peltz G, Pohl G, Liu E, Copley-Merriman K, Khan S, Kaye JA.; Cancer. 2011 Mar 1;117(5):884–96. doi: 10.1002/cncr.25644. Epub 2010 Oct 11. "Patients defined quality cancer care as being treated well by providers, having multiple treatment options, and being part of the decision-making process. Waiting to see providers, having problems with referrals, going to different locations for treatment, experiencing billing inaccuracies, and navigating managed care reimbursement negatively affected patients' quality-of-care perceptions."

[5] Hess, L.M., and G. Pohl. 2013. "Perspectives of Quality Care in Cancer Treatment: A Review of the Literature." Am Health Drug Benefits 6, no. 6, pp. 321–29. https://ncbi.nlm.nih.gov/pmc/articles/PMC4031722/
See Table 8.1 on service quality indicators from patients' perspectives.

[6] Harolds, J. 2015. "Quality and safety in Health Care, Part IV, Quality and cancer Care." Clinical nuclear medicine 40, no. 11, pp. 864–66. https://researchgate.net/publication/282658843_Quality_and_Safety_in_Health_Care_Part_IV_Quality_and_Cancer_Care

Table 8.1 Content of patient-reported cancer quality themes

Patient theme	Content
Information	**Defining:** help patients and families find reputable websites; navigators to help patients participate in decision-making; knowledge of how to manage side effects; care team helping patient to understand diagnosis; written information on what to expect during treatment, side effects, and what to do at home; knowing who to ask when there are questions **Barriers:** patients overwhelmed by amount of, complexity of, and conflicts in information; patient education provided after major decisions have been made; lack of awareness of what was going to happen, procedures not explained; not understanding test results; contradictory information; not knowing where to call after hours
Communication	**Defining:** high ratings of communication correspond to high ratings of quality care **Barriers:** inaccurate/contradictory information from interactions with providers; understandability of instructions or information given at diagnosis and during treatment decision-making
Coordination of care	**Defining:** find a "one-stop shopping" approach to cancer care; enhanced role of primary care provider during treatment; all providers working as a team **Barriers:** lack of teamwork among a variety of healthcare providers; disorganization between providers; lack of single source of information on treatment history, tests, and billing; primary care does not understand cancer and specialist is only familiar with cancer
Timeliness of care	**Defining:** patients getting a more rapid diagnosis and are more satisfied with care; timely care is in accordance with patient preferences, not just shorter time **Barriers:** problems with appointment systems or waiting times lead to missed appointments; takes too long to reach a provider when there is an urgent issue; delays during the diagnostic period increased distress; long wait times add to patient stress
Responsibility for care	Participatory decision-making associated with greater satisfaction; need to have clarity in who is responsible for which part of care; patients do not want to be left with the responsibility of making sure things are done correctly
Personalized care	Being cared for as a person rather than just as a patient; "whole person" approach to care; provider and staff knows you by name; high ratings of treatment by providers associated with willingness to recommend provider
Psychosocial support	Need for peer and professional psychosocial support for patients; need for emotional support from the healthcare provider; services need to be introduced earlier in the care plan; social support from family and friends
Lack of attention to care	Providers do not pay enough attention to the individual's care; patients have insufficient amount of time with the provider; lack of attention during inpatient stay and lack of respect have an impact on recovery

Source: Hess, L.M., and G. Pohl. 2013. "Perspectives of Quality Care in Cancer Treatment: A Review of the Literature." *Am Health Drug Benefits* 6, no. 6, pp. 321–29. https://ncbi.nlm.nih.gov/pmc/articles/PMC4031722/

Patient-Centric Treatment and Care Plan

Treatment with care, empathy, and compassion was once the only option available to the physicians. However, the developments in the medical field brought dramatic changes in the treatment of cancer that have benefited many patients: regular screening leading to early diagnosis, surgical treatments that are less radical and disfiguring, and more long-term disease-free survivors. Medical treatments focused more on saving lives and less on the quality of life of cancer survivors.

Trends in health services research and public health awareness have awakened the community to involve patients (and their families) in the design of cancer treatment and care. This move has led to "patient-centered care" and subsequently to patient-centric care. Patient-centered care is defined by the National Institutes of Health[7] as "health care that establishes a partnership among practitioners, patients and families (when appropriate) to ensure that decisions respect patients' wants, needs and preferences and solicit patients' input on the education and support they need to make decisions." Patient-centric healthcare differs in that the information and interactions emanate from the patient.

A patient-centric approach ensures that care is adaptable and targeted in addressing the WHAT-WHO-WHY concerns of patients and their families:

- What they are diagnosed with
- What the components are in their integrated treatment plan
- Who the members of the integrated multidisciplinary treatment and care team are
- How the patients will be treated
- How to deliver precision medicine at an individual level
- How their aspirations and personal wishes would be satisfied

[7] NIH website

Implementing a Patient-Centric Care Plan

In cancer care, communication between the patient and the consultant oncologist is the key to design a patient-centric treatment and care plan.[8]

Managerial challenges to design and develop patient-centric care plans are many. The design of a patient-centric care plan starts with gaining an understanding of what brings a patient to a hospital. There are three reasons:

- Referred case: A doctor–doctor referral case OR a doctor–hospital referral case
- Word of mouth: Community perception of service quality in a hospital
- Hospital stature: The hospital has been benchmarked as the best hospital for the particular line of treatment

Not all cancers are the same, and therefore not all cancer treatments are alike. Similarly, not all cancer patients are the same, and therefore each cancer patient should be treated based on a customized (personalized) treatment and care plan, based on the wishes, aspirations, and expectations of the patient, without compromising on medical service quality. A patient-centric treatment and care plan therefore calls for establishing excellent communication between the health care providers and patients.

Patient-Centric Care Plan: Patient's Perspective

What do the patients expect in a patient-centric care plan?

- Personal attention: What every patient wants is a physician who pays personal attention. Personal attention is an

[8] The NSW Cancer Plan focuses on patient-centred quality care across the cancer pathway, from prevention to treatment and survivorship and all of the Plan's activities contribute to a patient-centred quality cancer health care system.
Ref: Patient-centred quality cancer health care—Cancer Institute NSW; Published 1 December 2016
https://cancerinstitute.org.au/cancer-plan/focus

important determinant of patient satisfaction and facilitates the process of improving the quality of life during and after cancer treatment.

- Want to be heard: Every patient wants himself/herself to be heard clearly by the doctor: Is the doctor willing to listen to the patient's concerns, worries, and aspirations? Would the doctor be happy to be questioned by the patient?
- Better outcomes: Patients (community at large) expect better outcomes at the chosen hospital than other hospitals in the area. Better outcomes as perceived by the patients would include good quality of medical care and a good quality of life after medical treatment.
- Doctor's profile: Patients expect their doctors to be confident, empathetic, humane, personal, forthright, respectful, and thorough. Patients would look forward to good interpersonal relations with their doctor, as cancer survivors do engage with their doctors very frequently.
- Courteous staff: Patients expect the staff (from doctors to attendants) to be courteous, friendly, and make them comfortable. Good experiences during the hospital stay facilitate the healing process during and after cancer treatment. The old saying "State of the mind dictates the state of the body" cannot be better illustrated elsewhere.
- Knowledge: Patients want to understand their diseases and therefore are eager to acquire information/knowledge so that they can actively participate in making decisions about their treatment plans. Patients expect their service providers to inform them about possible changes in their emotional and social health.
- Physical layout: Patients expect the hospital layout (consultation room, waiting room, investigation room, etc.) to be pleasing, clean, and quiet.
- "Value for money": Patients expect "value for their money," good quality service at affordable charges. Cancer care is very expensive, and the outcomes not certain.

Message to Health Care Service Providers

Patients come first: The provider creating the plan of care should ensure that the patient's care plan will focus on addressing the patient's abilities, choices, beliefs, and values.

- Work as a team: It is always advisable for oncologists to work in teams, as cancer is still an enigma. Multidisciplinary teams with doctors from several departments (e.g., tumor board) provide an ideal forum to learn from group discussions and design an appropriate plan to meet patient needs without compromising on medical quality. Inform the patient only after a consensus has been reached in the tumor board.
- Partnering with patients: Discuss treatment protocols with the patients. If some patients question treatment protocols, please engage with them constructively and allay their doubts and fears about cancer and its treatment.
- Address the person and not the patient: Ask yourself what if the patient in front of you is your own son/daughter/sister/brother. Please see the person behind the cancer disease, and manage his/her hopes and aspirations.
- Understand the psyche of the patient: By gaining an understanding of the person (not just the disease), understanding the patient's psychological DNA becomes easier. Some patients are very positive, while many are scared of cancer. Identify those who can walk the cancer journey with their family members and those who need counseling.
- Psychosocial counseling: Understanding the person's DNA makes it easy to identify the nature of psychosocial counseling required to give the person a better quality of life. Recommend the appropriate counselor to the patient.
- Involve support groups: Introduce support group to the patients. Support groups include members who have walked the cancer journey and therefore understand the patients' concerns very well. By sharing experiences, it is possible to establish a rapport between the patients and support

groups and de-stress the patients so as to improve their quality of life.

- Financial counseling: It is necessary to discuss financial implications of cancer treatment with patients and their families. Try to design care packages so as to make the treatment affordable without compromising on medical quality.

Conclusion

There is enough evidence in the literature to demonstrate the effectiveness of patient-centric care plans over any other care plan for quality of life of cancer patients and survivors. Many hospitals in the developed world have implemented a patient-centric model by hosting regular tumor boards, multidisciplinary clinics, and precision medicine. Several hospitals[9] in the developing world are moving toward patient-centric approach to cancer care.

Globally, there is a move toward "person-centered care," a step beyond patient-centric care. A person-centered care is a holistic approach to treatment and healing, focusing on the person and not the patient, involving a combination of medical treatment, psychosocial counseling, and complementary therapies to improve the quality of life of cancer survivors.

[9] The HCG chain of cancer hospitals in India (the largest cancer care network in South Asia) is already practicing patient-centric cancer care.

CHAPTER 9

Conclusion

Case Study: Journey of Prema (Part 6)

Prema is cancer-free now. She is often asked about her cancer journey, and the response usually startles people: Yes, it is the best thing that ever happened to her. True, the treatment was dehumanizing. It first took her body, then her mind, and finally her soul. She had cancer and more importantly, she let it have her. Maybe it was the initial defense mechanism, wherein she allowed herself to surrender to it. However, the Prema who emerged cancer-free at the end of the treatment is a stronger person for it, physically and emotionally. Her attitude has changed: "I had cancer yes, but I will not let cancer have me."

She was forced to evaluate the way she had lived her life so far, with respect to herself and others. Cancer and chemotherapy gave her the impetus, strength, and courage needed to make the drastic changes. It gave her the strength to realize that if she could survive this, everything else would be a cake walk. She dropped all her past emotional baggage: anger, resentment, angst, and negative thoughts. She started a NEW NORMAL life, wherein attitudes of live and let live, having a positive outlook on life and whatever it threw at her, and peace were of utmost importance. She learned to forgive herself and love herself, and developed a steely inner strength. She learned to walk away from situations of negative energy anger, and confrontation. So yes, cancer is the best thing that ever happened to her. Today, she lives her life the way she feels she should always have. What more could she ask for, so thank you, God.

Prem has retired from service and is enjoying life at home. He keeps himself busy as a freelance consultant to hospitals.

Reviews of Breast Cancer: Medical Treatment, Side Effects, and Complementary Therapies

This slim volume addresses an issue that has not received the kind of attention it deserves: how one confronts the fact of breast cancer when one is struck down by the dreadful news and while cancer runs its course as it takes its course through one's body and mind. The fear it raises and the drastic nature of the treatment required remind us that the ancient Greeks had the same word—*pharmakon*—for both poison and cure. Survivors tell us that one who has not been through the process can have no understanding of the disturbances caused in the body by the treatment itself. Doctors, focused as they are on eradicating the cancer from the roots, do not, on the whole, say much about the side effects. It is this experience of enduring the treatment and dealing with the changes in the body and mind as they respond to the treatment that is the heart of this book.

The book is humanized through a brief commentary by the patient on her personal experience as she went through the phases with each of the specialists. The result is an unusual offering of an expert but simply written book made deeply personal by the "case study" in which the patient writes a single page at the start of each chapter telling us what it actually feels like to go through fear, pain, isolation, mood swings, and postoperative pain—the entire process before one emerges and is declared cancer-free. The caregiver's distress, which usually goes unnoticed, has been brought out, and the dedication speaks volumes as one realizes the weight of responsibility that rests on the caregiver, the anxiety that is involved in watching as a loved one suffers and, in life, is turned upside down.

The technical chapters are written with the general reader in mind and the information and explanations are lucid and highly useful. The chapter

on psychosocial issues draws attention to an aspect generally ignored and underscores the intertwining of body and mind. The chapter on alternative complementary therapies is helpful in that it offers a way out of great distress through the use of noninvasive techniques.

This work admirably fills a gap in what we may call the discourse around cancer. The writing is lucid and the approach compassionate and informed. It offers hope and clarity to breast cancer patients without overwhelming the reader. Its comprehensive perspective takes account of dimensions, some of which have not, on the whole, been seen as relevant. The unity underlying the voices in the team indicates not only good editing but also a sense that all team members recognize the importance of producing a book that will bring reassurance to breast cancer patients and their families.

—Prof Suguna Ramanathan (Retired), Dean, Arts faculty and
Head of the Department of English,
St Xaviers college, Ahmedabad, India

The case studies at the beginning of each chapter clearly brings out the experience of Prema and Prem when Prema was diagnosed with breast cancer; going through a whirl of tests, an explosion of information; a plethora of opinions and options; the fear and self-inflicted feeling of isolation and guilt; the strange experience of side effects about which no one warned them enough, and the financial implications. The authors have done an excellent search of available materials in the literature and presented the information in simple language for the patients and their families to understand the disease, meaningfully participate in decision making on treatment options, and in improving the quality of life of breast cancer survivors. I congratulate the authors for their efforts in writing this excellent and very informative book on breast cancer.

—Dr Shaleen Kumar, Professor and Head, Department
of Radiotherapy, Regional Cancer Centre, Sanjay Gandhi
Post-Graduate Institute of Medical Sciences, Lucknow, India

As a breast cancer survivor, I found this book on breast cancer very informative, insightful, and helpful. This book covers every possible aspect of the disease. Every possible question that could arise in the mind of the

patient and caregivers is answered in an optimistic tone. Through Prema's tortuous but successful cancer journey, the book brings out in lucid language, the medical, physical, psychological, sociological, economic, and other aspects of the disease and its treatment. The chapter on complementary therapies uniquely connects the vedic view of "koshas" with cancer. The focus on patient-centered cancer deserves a special mention. The authors deserve applause, because this approach is lacking in the Indian environment and is urgently required.

—Faculty, Gujarat University, Ahmedabad

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Breast Cancer

Medical Treatment, Side Effects, and Complementary Therapies

K. V. Ramani • Hemalatha Ramani • Shirish S. Alurkar • B. S. Ajaikumar • Riri G. Trivedi

A cancer prognosis has the tendency to knock patients and their family off their feet. Nothing can prepare people for the big "C" and it often feels like they are losing control over their own life, where nothing will be the same again.

This book takes readers through the journey of Prema (diagnosed with breast cancer) and Prem (her caregiver) and covers the whole gamut of processes in cancer treatment and care in a simple language: diagnosis, medical treatment options, physical and psychosocial side effects, complementary therapies, and the importance of patient-centric care to improve the quality of life of breast cancer survivors.

We hope future breast cancer patients and their families will benefit from our book and prepare themselves to face the challenges of dealing with breast cancer.

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ISBN: 978-1-94664-620-0
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