Patient Care Management of Cancer

By

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Declaration

It is hereby declared that

1. The thesis submitted is my/our own original work while completing degree at Brac University.
2. The thesis does not contain material previously published or written by a third party, except where this is appropriately cited through full and accurate referencing.
3. The thesis does not contain material which has been accepted, or submitted, for any other degree or diploma at a university or other institution.
4. I have acknowledged all main sources of help.

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Approval

The thesis/project titled “Patient Care Management of Cancer” submitted by Syeda Maliha Ahmed (15146032) of Spring, 2015 has been accepted as satisfactory in partial fulfillment of the requirement for the degree of Bachelor of Pharmacy on 29th May 30, 2019.

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Ethics Statement

This study does not involve any kind of animal or human trial.

Abstract

As estimated by the IARC, the global cancer burden has risen to 18.1 million new cases and 9.6 million deaths in the past year. Apart from other factors, limited access to timely diagnosis and treatment is one of the main reasons behind the high cancer incidence and death. This review aims to cover all the available screening methods for early detection, diagnostics and treatment methods currently available for cancer patients along with proper planning to ensure proper patient care management at each of these levels. Additionally, practical strategies for implementing patient care management for oncology care for both survivors and non-survivors, along with the barriers to care and future recommendations to overcome those barriers have been discussed.

Keywords: patient care management, palliative care, diagnosis delay, quality end-of-life care, pain management

Dedication

Dedicated to all the heroes who have lost their courageous battle with cancer.

Acknowledgement

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List of Acronyms

PCM	Patient Care Management
IARC	The International Agency for Research on Cancer
MDTs	Multidisciplinary Teams
WHO	World Health Organization
NCI	National Cancer Institute
PDA	Patient Decision Aids
CRC	Colorectal Cancer
USPSTF	United States Preventive Services Task Force
DGHS	Directorate General of Health Services
HNPSP	Health, Nutrition and Population Sector Program
CT	Computed Tomography
MRI	Magnetic Resonance Imaging
UV	Ultra Violet
ECS-CP	Edmonton Classification System for Cancer Pain
DN4	Douleur Neuropathique
CTC	Cell search circulating Tumor Cell
CBC	Complete Blood Count
PET	Positron Emission Tomography

QOL	Quality of Life
OCM	Oncology Care Model
NICE	National Institute for Health and Care Excellence
ACP	Advanced Care Planning
HCP	Health Care Provider
ED	Emergency Department

Chapter 1

Introduction

Patient care management (PCM) is a set of activities or a system that is planned to help patients and their families in handling medical conditions productively and efficiently. This system aims to upgrade a patient's health functionality, ameliorate the coordination among different care systems, reduce and terminate repetition of services, lower the need for costly therapeutic care and increase patient involvement in through self-care (Robert Wood Johnson Foundation, 2009). Activities of a patient care management system involve routine health examinations and screenings, making reviews and using them, focusing on events, case management of short-term events and long-term chronic conditions and diseases. One of the key components of care management is identifying patients most likely to benefit from it like high hospital users. Care management not only addresses the patients' biomedical context but also their social and psychological context (Himmel, Rogausch, & Sonnenhalde, 2014).

According to IARC, in 2018, the number of new cancer cases reported were estimated to be 18.1 million while 9.6 million people have been reported to die of cancer in the same year. Statistics show that the probability for men being affected by cancer is 20% and for women it is 16.7%, while the probability of death from cancer is 12.5% in men and 9.09% in women. The report by IARC suggested that all the new cases of cancer in 2018, 50% of them occurred in Asia while an even greater proportion of deaths from cancer were reported in the same year in Asia. One of the reasons behind this could be that Asia nearly has 60% of the world population. A mortality rate of 20.3% cancer deaths and 23.4% of the cancer cases happening worldwide were reported to be in Europe with only 9.0% of the world population while the Americans account for 21.0% cancer cases with 14.4% of mortality rate while consisting of 13.3% of the global population. The proportions of deaths due to cancer in Asia was 57.3%

and was 7.3% in Africa which are greater than the incident cases of cancer in other world regions because these regions have more prevalence for certain types of cancer. Likely reasons behind this difference are poorer disease prognosis, high mortality rates, inadequate access to diagnosis and treatment on time in numerous countries in Asia and Africa (International Agency for Research on Cancer (IARC), 2018).

In an aim to ameliorate the recent significant condition and distress due to cancer globally, successful and cost-effective programs can be implemented diagnose the disease early, screen regularly, treat and implement palliative care. Cancer can be treated using drugs, chemotherapy, radiation therapy or surgery based on the type of tumor, stage of cancer, availability of resources and the patients' preference of treatment options. Hence to maintain, coordinate and maximize the effectiveness of all these activities, patient care management has now become one of the critical components of the treatment process of cancer.

Cancer management is quite complicated and requires proper strategies to ensure the highest quality of individualized care being delivered on time for the patients. Targets can be designed and set to increase the competitiveness among healthcare providers along with improving overall care and services for the cancer patients. This process involves multidisciplinary teams (MDTs) working together in partnership to meet stated goals by delivering optimal care to the patients (Anderson, 2016). It has been seen that setting targets benefit the delivery of cancer care but can also lead to unexpected consequences. Targets enable separate healthcare providers to meet their individual goals, but on the other hand can conversely spoil all efforts (Anderson, 2016). One of the very well-known organizations working in cancer control is the World Health Organization (WHO). WHO sets norms and standards in an aim to encourage national cancer control plans, policies, and programs in harmony with WHO's plan of action for noncommunicable diseases and other health conditions. For cancer control, WHO has developed prevention, early diagnosis of the type of cancer, screening, treatment and palliative

care programs. Moreover, WHO encourages checking and evaluation with the aid of registries and research depending on the disease burden in different regions and the availability of the resources (World Health Organization (WHO), 2019b).

The objective behind this review is to highlight the current screening methods, treatments for cancer patients and the different types of patient care management strategies being adopted globally. The paper can be used as a recommendation to unravel the current barriers to care and suggest remedies to overcome these issues and raise standards for cancer care from where it currently stands globally and in low-income countries such as Bangladesh.

Chapter 2

Screening Methods for Early Detection of Cancer

In order to improve management of patient care, more experts are turning to shared decisions. It is believed that it aids patients in making more informed decisions that consider their values and preferences by allowing patients to take part complex critical medical decision making, starting from screening programs. The Affordable Care Act of 2010 directed the formation of "a program that develops, tests, and disseminates certificated patient decision aids." This directed shared decision-making tools development and these tools aid patients and their caregivers in understanding and communicating their preferences better about treatment options (National Cancer Institute, 2016).

One example of the implementation of shared decision is in breast cancer screening. Many mammography guidelines encourage women to consult with their healthcare providers about the positive and negative impact of mammography, the time to start screening and the frequency at which it should be done. In a study comparing the experiences and behavior of a group of people who were aided by a decision-making tool with a group of people who did not receive any such tools, the research team found out that informing patients about overdiagnosis through the decision-making tools made a difference. That particular group was able to make more informed decisions and was less worried about breast cancer. However, the target group were seen to have lower confidence in their decision about screening as they were no longer clear about their choice after the study team made their intervention (Hersch, Jansen, & McCaffery, 2018).

In another study a randomized trial was used to access an approach that is novel, for the use of patient decision aids (PDA), so that individualized decision making for colorectal cancer (CRC) screening for the elderly can be encouraged. The team concluded that targeting patients with patient decision aids (PDA) can be an effective way to promote the right kind of care among the older population (Lewis et al., 2018).

Even though shared decision-making tools have proved to give satisfactory output, not all shared decision-making tools are successful. Researching into the right kind of decision tools and their implementation in distinct populations is actively being researched on, in an effort to reduce overdiagnosis of many cancer types (National Cancer Institute (NCI), 2016).

2.1 What is Screening?

Checking up for cancer in a person before the development of any symptoms is called screening. This helps to diagnose cancer earlier in the disease trajectory and once this happens, it becomes easier to treat the disease (National Cancer Institute, 2019b).

It is believed that cancer screening programs have the ability to decrease cancer-specific mortality. The aim is to detect the cancer as early as possible before it starts to spread to different parts of the body. National Institute of Cancer Research Hospital (NICRH) Director Prof Dr Md Mosharraf Hossen emphasized that early detection of cancer increases the chance of cure to 80% (Dhaka Tribune, 2019). Additionally, early detection makes management of cancer comparatively easier. The United States Preventive Services Task Force (USPSTF) has to say that, patients benefit from screening for breast, cervical, lung and colorectal cancer even if they have to rely on the least sufficient evidence (Ebell, Thai, & Royalty, 2018). Other developed countries are seen to have many

screening programs as well. In European countries, more than 31 million women were considered for breast cancer screening. Among them 24.5 million women were invited to screen and 15.2 million of them were screened for cancer (Ebell et al., 2018). Deaths due to breast cancer has been reduced from 31.4 to 20.5 deaths per 100,000 women from the year 1975 to the year 2014 in the USA, and similar trends have been observed in Europe as well (Ebell et al., 2018). Hence it is believed that screening for cancer is beneficial as it can lead to improved treatment (Ebell et al., 2018).

Currently, scientists are trying to better comprehend and infer the type of people or population are more prone to certain types of cancer. As a part of their research, they study people's activities and the factors causing cancer. It is also essential to keep in mind that the results and recommendations of a cancer screening test does not necessarily indicate the incidence or presence of cancer in a patient (National Cancer Institute, 2019b).

Cancer screening programs have large implementation in high-income countries that have greater availability of resources (Ebell et al., 2018). However, for low income countries like Bangladesh, early detection of cancer may be strategized in such a way that it educates the population about the improved access to primary care and also about the signs and symptoms. Such strategies may also aim to dismiss the age long negativity about cancer that still discourages people to seek medical advice. Through increased awareness a lot of lives may be saved as many cancers that have the potential to be cured at an early stage are only detected in advanced stages (DGHS, 2008). Early detection of the 3 most prevalent types of cancer such as cervical, breast and oral cancer have already been taken into consideration by Bangladesh Government under the Health, Nutrition and Population Sector Program (2003-2010). All these

are potentially curable cancer types and requires good treatment facilities, supportive and rehabilitative facilities in the country (DGHS, 2008).

3.2 Screening Methods

There are many screening methods available based on the type of cancer. Some of them are mentioned below:

3.2.1 Colonoscopy, Sigmoidoscopy, and Stool Tests (High-Sensitivity Fecal Occult Blood Tests and Stool DNA Tests)

Numerous screening methods have reduced death risks from colorectal cancer. Colonoscopy and sigmoidoscopy are two such screening methods that have been seen to be effective in identifying colorectal cancer in advance. They do this by finding polyps that needs to be removed from the body before they become malignant. Experts suggest people with higher chances of developing colorectal cancer to have either colonoscopy or sigmoidoscopy done between the age of 50 to 75 (National Cancer Institute, 2019b).

3.2.2 Low-Dose Helical Computed Tomography

This test is done to investigate the presence of lung cancer. It has been found to bring down deaths due to lung cancer in heavy smokers between the age of 55 to 74 (National Cancer Institute, 2019b). In a study conducted at 33 U.S. medical centers from the year 2002 to 2004, it was found that screening using low-dose CT reduced loss of lives due to lung cancer (National Lung Screening Trial Research Team et al., 2011).

3.2.3 Mammography

This method has shown to reduce deaths from breast cancer among women between the age of 40 to 74, especially those over age 50 (National Cancer Institute, 2019b).

3.2.4 Pap Test and Human Papillomavirus (HPV) Testing

Pap test and HPV tests can be done both alone and in combination. They have been proved to detect cervical cancer early and also prevent it. As recommended, the testing should begin and end at the age of 21 and 65 respectively in women (National Cancer Institute, 2019b).

3.2.5 Other Screening Tests

Other screening tests that are not sufficiently effective as the ones mentioned before may still be offered to people who are more prone to cancer.

3.2.5.1 Breast MRI

The breast MRI is an imaging technique used to screen women carrying the *BRCA1* gene or the *BRCA2* gene which are harmful mutations and causes higher chances of developing mostly breast cancer (National Cancer Institute, 2019b).

3.2.5.2 Clinical Breast Exams and Regular Breast Self-Exams

Routine clinical breast examination or self-examination have not been found to be sufficiently effective in turning down breast cancer deaths. Despite this, a lump or any other unusual changes in the breast still calls for a further examination (National Cancer Institute, 2019b).

3.2.5.3 Skin Test

According to doctors, people more prone to having skin cancer should have their skin examined regularly. These include people with a family history of skin cancer, lifestyle and exposure to chemicals and UV rays, immune suppression and certain age, gender and skin tones (Cancer Treatment Centers of America (CTCA), 2019b). Even though such examinations don't reduce deaths due to skin cancer and have chances of overtreatment, it helps to raise awareness (National Cancer Institute, 2019b).

3.2.5.4 Transvaginal Ultrasound

This imaging test is used in women who are more prone to having ovarian cancer for having *BRCA1* or *BRCA2* gene mutation. It is also done to screen for endometrial cancer due to the presence of a condition called Lynch syndrome. However it still has not seen to be sufficiently effective in reducing deaths from either cancer (National Cancer Institute, 2019b).

3.2.5.5 Virtual Colonoscopy

This test examines the colon and rectum externally. Even though it does not reduce colorectal cancer mortality, it may still come to use if it is the only acceptable screening method for colorectal cancer screening test to the patient. Colonoscopy may disclose complications external to the colon that might then need further investigation (National Cancer Institute, 2019b).

3.2.6 Tumor Marker Tests

Tumor markers assist to uncover, diagnose, and help manage some types of cancer. Even though a high level of a tumor marker may indicate malignancy, this alone cannot diagnose cancer. Hence, additional tests like biopsies are combined with measurements of tumor markers to diagnose cancer (National Cancer Institute, 2019b).

Tumor markers are also useful for staging and prognosis of some types of cancer (National Cancer Institute, 2019b). During cancer therapies, tumor markers are measured periodically to check for improvements of the patients' condition and also to check whether the malignancy is coming back once the treatment has been completed (National Cancer Institute, 2019b).

The most common tumor markers in use are (National Cancer Institute, 2019b):

***ALK* gene rearrangements and overexpression:** Used for tumor analysis of certain types of lung cancer and lymphoma.

AFP: Used for the hematological analysis of liver cancer and germ cell tumors of the germ cells.

B2M: Used for certain types of lymphoma, leukemia, and myeloma.

Beta-hCG: Used for choriocarcinoma and germ cell tumors of the germ cells.

***BRCA1* and *BRCA2* gene mutations:** Used for hematological analysis of ovarian cancer.

BCR-ABL fusion gene (Philadelphia chromosome): Analyses blood and/or bone marrow for certain types of leukemia.

BRAF V600 mutations: Used for tumor analysis of cutaneous melanoma and colorectal cancer.

C-kit/CD117: Used for tumor analysis of gastrointestinal stromal tumor and mucosal melanoma.

CA15-3/CA27.29: Used for hematological analysis of breast cancer.

CA19-9: Used for hematological analysis of gastric, pancreatic, bile duct and gallbladder cancer.

CA-125: Used for hematological analysis of ovarian cancer.

Calcitonin: Used for hematological analysis of medullary thyroid cancer.

CEA: Used for hematological analysis of colorectal cancer and some other cancers.

CD20: Used for hematological analysis of non-Hodgkin lymphoma.

CgA: Used for hematological analysis of neuroendocrine tumors.

Chromosomes 3, 7, 17, and 9p21: Used for urine analysis for cancer of the bladder.

Circulating tumor cells of epithelial origin (CELLSEARCH): Used for hematological analysis of metastatic breast, prostate, and colorectal cancers.

Cytokeratin fragment 21-1: Used for hematological analysis of lung cancer.

***EGFR* gene mutation analysis:** Used for tumor analysis of certain type of lung cancer.

ER/PR: Used for tumor analysis of breast cancer.

Fibrin/fibrinogen: Used for urine analysis for cancer of the bladder.

HE4: Used for hematological analysis of ovarian cancer.

HER2/neu gene amplification or protein overexpression: Used for tumor analysis of breast and gastric cancer, and gastroesophageal junction adenocarcinoma.

Immunoglobulins: Used for multiple myeloma and Waldenström macroglobulinemia.
***KRAS* gene mutation analysis:** Used for tumor analysis of colorectal cancer and a certain type of lung cancer.

Lactate dehydrogenase: Used for hematological analysis of tumors of the germ cell, lymphoma, leukemia, melanoma, and neuroblastoma.

Neuron-specific enolase (NSE): Used for hematological analysis of certain type of lung cancer and neuroblastoma.

Nuclear matrix protein 22: Used for urine analysis for cancer of the bladder.

PD-L1: Used for tumor analysis of certain type of lung cancer.

Prostate-specific antigen (PSA): Used for hematological analysis of prostate cancer

Thyroglobulin: Used for hematological analysis of thyroid cancer.

uPA and PAI-1: Used for tumor analysis of breast cancer.

5-Protein signature: Used for hematological analysis of cancer of the ovary.

21-Gene signature: Used for tumor analysis of breast cancer.

70-Gene signature: Used for tumor analysis of breast cancer.

3.2.7 Screening for Cancer-Associated Pain

Pain is an individual sensation that is affected by a person's genes, attitude and etc. There are numerous staging systems for pain, one such is the Edmonton classification system for cancer pain (ECS-CP) which was developed to stage cancer pain and predict medical condition (Money & Garber, 2018). This staging system classifies pain based on whether it follows the nociceptive or neuropathic mechanism, existence of breakthrough pain, psychological distress, any sort of addiction, or any compromised cognitive function (Money & Garber, 2018). Afterwards, patients are classified among standards 1 to 3, with level 3 being the most risky classification with less desired prognosis and treatment response (Money & Garber, 2018).

Another assessment tool for pain based on functional impairment is the Karnofsky performance status scale (Money & Garber, 2018). This scoring system designates function levels based on percentages with 0% being deceased and 100% completely functional. The aim of this scale is to assess patients' medical condition and improvement after treatment from a functional standpoint (Money & Garber, 2018).

The most convenient scoring system for emergency rooms is called the Zubrod score (Money & Garber, 2018). It is a very simple scoring system that designates scores from 0 to 4 to cancer patients with 0 being completely functional and 4 being bedridden. Scores from 0 to 2 means

patients can live independently with least or no assistance at all. Scores from 3 to 4 means patients need to be under observation and also require nursing care (Money & Garber, 2018).

The douleur neuropathique (DN4) interview came into being for the evaluation of neuropathic pain (Money & Garber, 2018). It consists of a number of questions with answers being either a yes or a no and is done by the clinician. The scoring system range from 0 to 10, where scores higher than 4 means patients are highly likely to suffer from neuropathic pain (Money & Garber, 2018).

Once the screening examinations are done, if the test results are abnormal, it would be necessary to have more tests done for confirmation. These are called diagnostic tests (National Cancer Institute, 2019b).

Chapter 3

Diagnosis of Cancer

If any symptom or the cancer screening test results suggest any presence of malignancy, the doctor needs to confirm it through personal and family medical history and further physical examinations including lab tests, imaging procedures, biopsies or procedures (National Cancer Institute, 2015b).

Cancer has been politically proclaimed to be an acute disease. Hence diagnosis and treatment for cancer needs to be done with no delays (Probst, Hussain, & Andersen, 2012). It has been seen in the recent years that specific strategies are being implemented for ensuring timely cancer diagnosis by a number of health care systems (Vedsted & Olesen, 2015). The reasons behind this are poor cancer control and public dissatisfaction when it comes to diagnostic waiting times (Vedsted & Olesen, 2015). These information were backed up by reports when they showed low cancer survival rate in UK and Denmark compared to other countries as in Denmark, the cancer patients are treated at a later stage, clearly suggesting delays in the presentation, diagnosis and treatment (Vedsted & Olesen, 2015). If the cancer patients, after the completion of their treatment, were asked about the aspects of the entire pathway that they considered to be most important, they reported them to be referrals, diagnosis, treatment and the time they spent waiting for all investigations results starting from the first ones prescribed by a general physician (Booij et al., 2013). Some specific strategies are being developed and implemented by countries like Denmark, who tend to suffer from lower cancer survival rate, to combat the aforementioned issues. One such strategy is the Danish three-legged strategy which is a modified approach to referrals from general practitioners to expedite the cancer diagnosis process (Vedsted & Olesen, 2015). In the United Kingdom, a new priority–setting approach called PRIORITIZE has been developed and implemented that aims to recognize the

core issues and solutions cancer care clinicians come up with related to diagnostic delays (Car et al., 2016). Both these strategies aim to prevent diagnosis delay for cancer patients as every minute counts for a person who is fighting a deadly disease like cancer. Expedited diagnosis of cancer with symptoms are likely to benefit patients by improving survival, allowing earlier-stage diagnosis and ameliorating quality of life (Neal et al., 2015a). However, these benefits vary between cancers (Neal et al., 2015a). Hence it can be stated that such strategies to prevent diagnosis delay or expedite the diagnosis process are contributing to better patient care management for cancer.

3.1 Lab Tests

Deviations from normal level of certain body substances can indicate the presence of cancer. Hence, lab tests that measures such substances in the blood, urine or other body fluids can help diagnose cancer. Even though lab tests are important for cancer diagnosis, they cannot be relied alone for diagnosis as unusual lab results do not confirm cancer incidence (National Cancer Institute, 2015b).

Some of such laboratory tests are listed below.

3.1.1 Genetic Testing

This test maps a patient's genetic profile and thus can identify any hereditary irregularities or susceptibilities which may cause health complications, for example higher chances of developing cancer (Cancer Treatment Centers of America (CTCA), 2019a).

3.1.2 Advanced Genomic Testing

Genomic tumor assessments can be used to deduce any changes in the DNA that causes tumor growth and can help to modify treatments according to need to target any anomaly in a particular tumor (Cancer Treatment Centers of America (CTCA), 2019a).

3.1.3 CellSearch Circulating Tumor Cell (CTC) test

Cell search circulating tumor cell (CTC) tests monitor prostate, colorectal and metastatic breast cancer. CTCs are the detached cancer cells from the solid tumors that enters into the bloodstream. This test captures, identifies and counts the tumor cells that circulates in a blood sample (Cancer Treatment Centers of America (CTCA), 2019a).

3.1.4 Complete Blood Count Test

A complete blood count (CBC) test measures the amount of blood cells, platelets, hemoglobin and hematocrit in the blood. This test is used to detect conditions like leukemia, anemia and infection (Cancer Treatment Centers of America (CTCA), 2019a).

3.1.5 Flow Cytometry

Flow cytometry is a test used to identify and categorize particular types of cancers, like leukemia and lymphoma. It measures different characteristics of the cells present in a bone marrow or blood sample. This is also useful in measuring the amount of DNA a cancer cell contains (Cancer Treatment Centers of America (CTCA), 2019a).

3.1.6 Fine Needle Aspiration Cytology (FNAC) Test

Fine needle aspiration cytology (FNAC) uses a narrow gauge needle to collect a sample of a lesion for microscopic examination (Roskell & Buley, 2004).

3.1.7 Mammaprint and Blueprint test

The Mammaprint 70-Gene Breast Cancer Recurrence Assay determines the likelihood of recurrence of cancer in a patient. The Blueprint 80-Gene Molecular Subtyping Assay investigates a tumor's specific mutations that dictates the behavior of the malignancy. If used along with Mammaprint assay, Blueprint is able to classify tumors, that may help in decisions related to treatment (Cancer Treatment Centers of America (CTCA), 2019a).

3.1.8 Oncotype DX test

The Oncotype DX lab test helps decide whether chemotherapy is going to be beneficial for patients suffering from early-stage breast cancer and to check for recurrence. The test is done using a tissue sample removed during a breast cancer surgery (Cancer Treatment Centers of America (CTCA), 2019a).

3.2 Imaging Procedures

Imaging procedures capture pictures for locating and diagnosing cancer (National Cancer Institute, 2015b).

These pictures can be formed in various ways:

3.2.1 Computed Tomography (CT) Scan

In an CT scan, an x-ray machine is connected to a computer to take a set of comprehensive pictures of the organs. A dye can be used in addition as a contrast material to focus on the parts inside the body (National Cancer Institute, 2015b).

3.2.2 Nuclear Scan

A minute portion of a radioactive substance is injected (also known as tracer) for this type of scan. The tracer travels along the bloodstream and collects in particular parts of the body. Then, a scanner is used to detect and measure the radioactivity by creating images of bones or organs either digitally or on a film. Nuclear scan may also be called radionuclide scan (National Cancer Institute, 2015b).

3.2.3 Ultrasound

In this process, an ultrasound device transmits sound waves that reflect off body tissues like an echo which are then collected by a computer to generate a picture of the areas the sound reflected off. This picture is known as a sonogram (National Cancer Institute, 2015b).

3.2.4 Magnetic Resonance Imaging (MRI)

In this process, a magnet of good strength is connected to a computer is used to make detailed pictures of areas in the body. Magnetic resonance is used to elucidate structures inside the body (National Cancer Institute, 2015b).

3.2.5 Positron Emission Tomography (PET) Scan

For this scan, the patient is injected with a tracer and a machine creates three dimensional pictures of the areas the tracer collects inside the body. These scans are able to represent the functionality of organs and tissues inside the body (National Cancer Institute, 2015b).

3.2.6 X-rays

X-rays use minute amount of radiation to construct images of the inside of the body (National Cancer Institute, 2015b).

3.3 Biopsy

In a biopsy test a sample of tissue or fluid from the patient's body is removed by a doctor and is later inspected for malignancy by a pathologist. If the cells are found to be cancerous, a biopsy additionally may help determine the site of origin of the cancer if the results turn out to be positive for malignancy (Cancer Treatment Centers of America (CTCA), 2019a).

Some common sites for biopsies include the breast, skin, bone marrow, gastrointestinal tract, lung, liver, bladder, colon and lymph nodes. The method of biopsy is determined by the doctor based on several factors, such as the characteristics, shape, size, and location of the abnormality (Cancer Treatment Centers of America (CTCA), 2019a).

Some types of biopsy have been listed below.

3.3.1 Bone Marrow Aspiration and Biopsy

Bone marrow biopsies can be helpful in diagnosing and monitoring a variety of hematologic cancers, such as leukemia, lymphoma and multiple myeloma (Cancer Treatment Centers of America (CTCA), 2019a).

3.3.2 Image-Guided Biopsy

Image-guided biopsy is recommended by the doctor when the tumor cannot be seen or felt externally, or the tumor lies deeper inside the body which only appears on imaging scan. Such tests include (American Society of Clinical Oncology (ASCO), 2019a):

- CT-guided biopsy
- MRI-guided biopsy

- Ultrasound-guided biopsy
- Fluoroscopy-guided biopsy
- X-ray-guided biopsy

3.3.4 Fine Needle Aspiration Biopsy

In a fine needle aspiration biopsy, the doctor collects a small amount of tissue from the area of abnormality to examine (American Society of Clinical Oncology (ASCO), 2019a).

3.3.5 Core Needle Biopsy

This procedure makes use of a larger needle to extract a larger tissue sample (American Society of Clinical Oncology (ASCO), 2019a).

3.3.6 Vacuum-Assisted Biopsy

This procedure uses a suction device to collect a tissue sample through a modified needle (American Society of Clinical Oncology (ASCO), 2019a).

3.3.7 Excisional Biopsy

In this type of biopsy, the doctor pulls out the entire area of abnormality (American Society of Clinical Oncology (ASCO), 2019a).

3.3.8 Shave Biopsy

The doctor makes use of a sharp tool to shave off tissue from the surface of the skin for this type of biopsy (American Society of Clinical Oncology (ASCO), 2019a).

3.3.9 Punch Biopsy

A sharp, circular tool is inserted into the skin by a doctor to take a sample from below the surface of the skin in a punch biopsy (American Society of Clinical Oncology (ASCO), 2019a).

3.3.10 Endoscopic Biopsy

Doctors use this method to take tiny samples of the tissue using forceps (American Society of Clinical Oncology (ASCO), 2019a).

3.3.11 Laparoscopic Biopsy

This procedure is used for the abdomen and is similar to an endoscopic biopsy. The camera helps the doctor find any abnormal areas to be able to insert a small needle and take a tissue sample from that area (American Society of Clinical Oncology (ASCO), 2019a).

3.3.12 Liquid Biopsy

This procedure tests a blood sample for cancer. Compared to a tissue biopsy, a liquid biopsy allows to be performed multiple times and can also be used to check for tumor progress and treatment response (American Society of Clinical Oncology (ASCO), 2019a).

3.3.13 Sentinel Lymph Node Biopsy

Sentinel lymph node biopsy diagnoses and stages cancer by determining whether cancer has spread (Cancer Treatment Centers of America (CTCA), 2019a).

Chapter 4

Treatment methods for cancer

Once a patient has been diagnosed with cancer, the patient will be requiring medical treatment and specialized care for months, and more often for years. According to the National Cancer Institute, the different modes of treatment therapy for cancer include – surgery, radiotherapy, chemotherapy, immunotherapy, targeted therapy, hormone therapy, stem cell transplant and precision medicine (National Cancer Institute, 2019d). Additionally, American Cancer Society mentions hyperthermia, photodynamic therapy, blood transfusion and donation and lasers as other procedures and techniques used in the treatment of cancer (American Cancer Society, 2019b). These treatment methods may be used alone or in combination to get desired outcomes. Once the treatment has been successfully completed, specific rehabilitation may be needed for the patient and sometimes also for the patients' caregivers. When the cancer treatment is known to be not curative, priority is to maintain the highest possible quality of life for the patient. For many patients, supportive, palliative and hospice care are essential and to ensure that patients receive such care, a range of professional services are required to be provided that extends beyond the discipline of oncology.

4.1 Types of Treatment

4.1.1 Surgery

During a cancer surgery, a surgical oncologist removes the entire malignant tumor or a part of the tumor and it's nearby tissues during an operation (National Cancer Institute, 2015d) (American Society of Clinical Oncology (ASCO), 2019b). Surgery works best for patients having solid tumors located in a particular area and can be of two types – an open surgery in which one large cut is made to remove the tumor or a minimally invasive surgery in which a

few small cuts are made to extract the tumor from the body (National Cancer Institute, 2015d). Other methods of surgery without cuts or scalpels include:

Cryosurgery: In Cryosurgery, extreme cold producing argon gas or liquid nitogen is used to kill abnormal tissues in the body and may be used in the treatment of primary-stage skin cancer, retinoblastoma, and abnormal growths on the skin and cervix before any malignancy develops (National Cancer Institute, 2015d).

Lasers: Lasers can be used to heat and destroy small areas (such as some tumors) in the treatment of cancer. The main types of lasers currently being used in cancer treatment include carbon dioxide, argon and neodymium: yttrium aluminum garnet (Nd:YAG). Lasers work in one of the two ways – it either shrinks or destroys a tumor with heat or activates a chemical called photosensitizing agent (called the Photodynamic therapy) that kills only the cancer cells (American Cancer Society, 2016).

Hyperthermia: In the hyperthermia treatment, high temperature is applied to certain parts of the body tissue. The extreme heat damages and kills cancer cells or makes them more vulnerable to radiation and particular chemotherapeutic drugs. One example of such treatment is radiofrequency ablation in which high-energy radio waves are used to generate heat (National Cancer Institute, 2015d).

4.1.2 Radiation Therapy

Radiation therapy, also known as radiotherapy, makes use of high radiation doses to kill cancerous cells and to reduce tumor sizes (National Cancer Institute, 2019a). The radiation makes small breaks in the DNA inside the cancer cells and these breaks prevents the cells from growing and dividing, eventually causing them to die (American Cancer Society, 2018). There are mainly two kinds of radiation therapy:

External Beam Radiation Therapy: is the therapy in which the radiation is targeted at the cancerous cells (National Cancer Institute, 2019a).

Internal Radiation Therapy: is the therapy in which the radiation source, which can be either solid or liquid, is put inside the body (National Cancer Institute, 2019a).

4.1.3 Chemotherapy

Chemotherapy uses agents called the chemotherapeutic agents that cause death of cancer cells by preventing cell division, targeting food sources of the cancer cells, motivate apoptosis and stop growth of blood vessels that supply a tumor (Medical News Today, 2017). There are different types of chemotherapeutic drug as well as different ways of receiving them. The major categories of chemotherapeutic agents include:

Alkylating agents cause inter- or intra-strand DNA crosslinks which in turn destabilizes DNA while it replicates (e.g., cyclophosphamide) (Galluzzi et al., 2015).

Antimetabolites stops DNA, RNA, or their building block synthesis (e.g., 5-fluorouracil) (Galluzzi et al., 2015) .

Topoisomerase inhibitors obstructs DNA from unwinding properly during replication and transcription (e.g., irinotecan) (Galluzzi et al., 2015).

Microtubular poisons inhibits the mitotic spindle by interfering with the polymerization or depolymerization of tubulin (e.g., paclitaxel) (Galluzzi et al., 2015).

Cytotoxic antibiotics exert antineoplastic effects through DNA intercalation and by high generation of reactive oxygen species (e.g., bleomycin) (Galluzzi et al., 2015).

4.1.4 Immunotherapy

Immunotherapy is a type of biological therapy that makes use of substances from the living organisms like antibodies to treat cancer as it helps the patients' immune system to fight cancer. This therapy isn't used as widely as surgery, radiation therapy or chemotherapy. Different immunotherapies are given in different routes – intravenous, oral, topical or intravesical (National Cancer Institute, 2018). Types of immunotherapy that directly act against cancer are:

Checkpoint Inhibitors: These drugs do not directly act on tumors rather they make cancer cells more prone immune system attack (National Cancer Institute, 2018).

Adoptive Cell Transfer: This enhances the innate ability of body's T cells to attack cancerous cells. In this treatment, the T cells are extracted from the tumor itself (National Cancer Institute, 2018).

Monoclonal Antibodies: Monoclonal antibodies attach to specific targets on cancer cells in one of the two ways: by making cancer cells more identifiable and easier to be destroyed by the immune system, and others are used in cancer treatment as targeted therapy, rather than immunotherapy. Small molecule drugs are also used for targeted therapy for cancer (National Cancer Institute, 2018).

Treatment Vaccines: This treatment boosts body's immune system response to cancer cells and does not function in the same way as vaccines that help prevent disease (National Cancer Institute, 2018).

The kinds of immunotherapy that work by enhancing body's immune system to help battle cancer are:

Cytokines: Cytokines are body cell manufactured natural proteins that play vital roles in body's immune responses. Interferons and interleukins are the two main kinds of cytokines in cancer treatment (National Cancer Institute, 2018).

BCG: BCG stands for Bacillus Calmette-Guérin and is used for bladder cancer treatment with an attenuated form of the bacteria responsible for tuberculosis. BCG provokes an immune response when it is inserted directly into the bladder using a catheter (National Cancer Institute, 2018).

4.1.5 Hormone Therapy

Hormone therapy treats cancer either by lessening the chances of reoccurrence of cancer or by slowing its progression or it is used to ease the symptoms of cancer unable to be treated through surgery or radiation therapy as means of treatment. It is used for prostate and breast cancer who requires hormones to grow (National Cancer Institute, 2015a).

4.1.6 Stem Cell Transplant

Stem cell transplants is one of the treatment methods available mostly for the cancer of the blood or the immune system. The transplantation occurs for peripheral blood, bone marrow and cord blood usually (American Cancer Society, 2019a).

The means of action for this treatment method is usually indirect. It works by helping the human body regain the stem cell producing capability after rigorous therapies like radiation or chemotherapy (National Cancer Institute, 2015c). However, the method may have a direct mode of action in case of multiple myeloma and certain types of leukemia (National Cancer Institute, 2015c). There are mainly two types of transplants based on the donor of the stem cells.

Autologous: The stem cells of own self (American Cancer Society, 2019c).

Allogeneic: The stem cells come from a matched relative or unrelated donor (American Cancer Society, 2019c).

4.1.7 Precision Medicine

Precision medicine aims to treat patients depending on the understanding of the genetic profile of the disease and can also be called personalized medicine (National Cancer Institute, 2017). Current research aims to find out whether cancer-causing genetic change targeted treatments in tumors are effective or not. Such drugs are also known as targeted therapies (National Cancer Institute, 2017).

4.1.8 Treatment for Cancer Associated Pain

Once the etiology and cause of the pain of the cancer patient is evaluated, suitable treatments methods can be determined (Money & Garber, 2018):

Neuropathic Pain Medications: Gabapentin and pregabalin are the drug of choice for neuropathic pain (Money & Garber, 2018).

Tricyclic Antidepressants (TCAs): Imipramine, clomipramine, nortriptyline and amitriptyline are examples of TCAs.

Serotonin Noradrenaline Reuptake Inhibitor (SNRI): Duloxetine is a drug that works by inhibiting the reuptake of serotonin and norepinephrine and is also a drug of choice for neuropathic pain (Money & Garber, 2018).

Anesthetics: Ketamine is a dissociative anesthetic for managing complex acute and chronic pain. Lidocaine is a local anesthetic structurally similar to cocaine. Magnesium is another atypical anesthetic (Money & Garber, 2018).

NSAIDs: Nonsteroidal anti-inflammatory drugs (NSAIDs) are used both topically as well as orally. The most commonly used NSAID for topical application is diclofenac.

Opioids: Opioids can either be short acting or long acting. Short acting opioids useful in the emergency room setting include morphine, hydrocodone, tapentadol, etc whereas long-acting, or extended release formulations of opioids include fentanyl, methadone, extended release morphine (ER), etc.

Opioid Ladder: WHO has developed a three-step "ladder" for cancer pain relief in adults (Figure 1). Prompt oral administration of drugs in the following order is necessary if pain occurs (World Health Organization, 2013):

i. Nonopioids (aspirin and paracetamol)
ii. Then, as necessary, mild opioids (codeine).
iii. Then strong opioids such as morphine, until the patient is free of pain.
iv. To calm fears and anxiety, additional drugs adjuvants should be used.

To ensure that patients are free from pain, the drugs should be administered every 3 to 6 hours rather than on “on-demand” (World Health Organization, 2013). It is inexpensive in nature and is 80-90% effective. If this method is not completely effective for patients, surgical interventions can be used on appropriate nerves for further pain relief. In case of children, WHO recommends a two-step opioid ladder (World Health Organization, 2013).

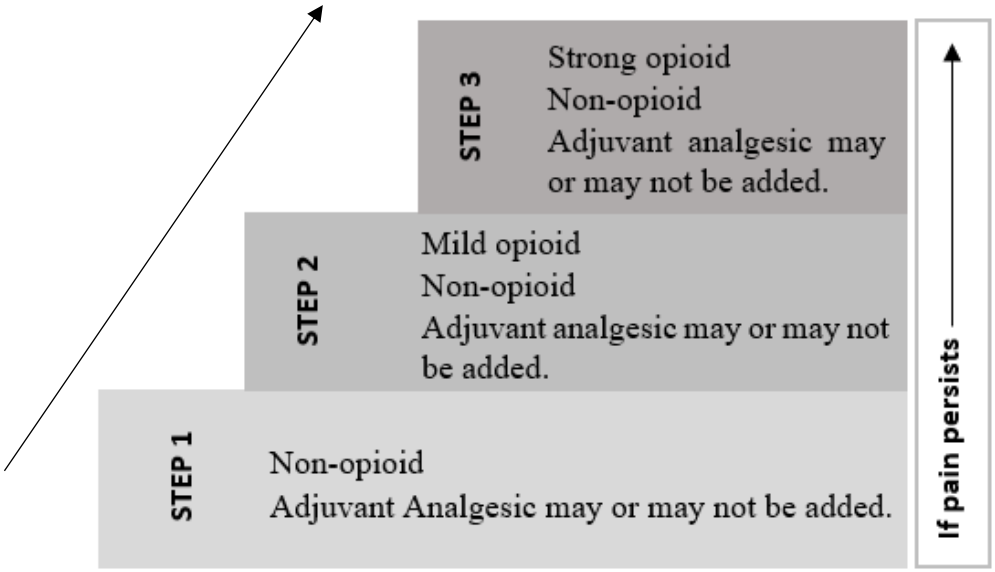

Figure 1: WHO's Opioid Ladder for Cancer Associated Pain (World Health Organization, 2013)

Chapter 5

Care Management

5.1 What is Care Management?

Care management can be defined by a range of activities that holistically aims to improve patient care by helping patients and caregivers manage health conditions more effectively and hence reduce the need for medical services (Staheli, 2017).

The goal of a care management system is to increase patient satisfaction, improve outcomes, cost reduction of the health care system through avoidance of unnecessary hospital and emergency department utilization (American Academy of Family Physicians (AAFP), 2019). A care management activities and services are shown below (Figure 2).

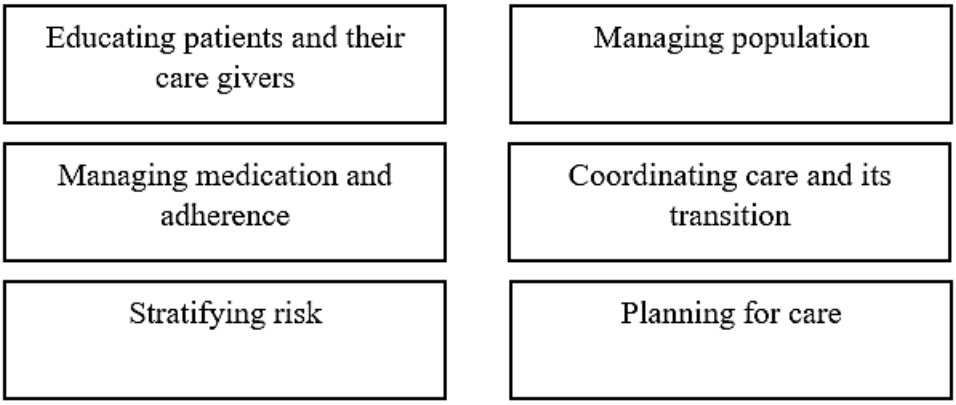

Figure 2: The Activities And Services Of A Care Management System (American Academy of Family Physicians (AAFP), 2019).

A care management system needs to be thorough, broad in scope and focused on analytics to be effective (Staheli, 2017).

For a care management to be all-inclusive, along with electronic storage of medical records and maintenance of coordination among the interdisciplinary care teams, other additional activities need to be included into the system as well to meet patient needs. If a care

management system is to be evaluated based on comprehensiveness, the following five competencies must be considered (Figure 3):

Figure 3: The 5 Main Skills Of Care Management (Staheli, 2017).

Data integration is the skill that retrieves data from multiple electronic medical records and other data sources and then analyzes the data to make it timely available to the right people. The second skill means making decisions using analytics to detect patients at significant risks and in greater need of its implementation. Care coordination is the timely communication and collaboration of the care team. Patient engagement involves guiding patients regarding their care plans and encouraging communication among all the members of the care team through several activities. Performance measurement refers to evaluation of the performance of the care-team (Staheli, 2017).

Another area that a care management system should be effective in is inclusivity. A care management system must not only be limited to a one electronic medical record and should target a pool of other data sources. This will enable strong interaction among the care team, comprising of providers of acute, primary and specialty care, patients, social workers, therapists and care managers. Lastly, analytics in the care management system is necessary to study data to track trends that drive better patient outcomes as well as improved workflow for the clinicians (Staheli, 2017).

5.2 Case Study of a Care Management System

Several models for patient care management are available or are being invented for different disease conditions and populations. One such personalized patient management system for cancer patients is called the OnkoNetwork. OnkoNetwork is an integrated personalized model for care that has been newly established in Hungary. It manages patients from the secondary care with first suspect of solid tumor (Pitter et al., 2019). OnkoNetwork came to establishment in July 2014 when the cancer mortality in Hungary was extremely high and the Strategic Director of the Móritz Kaposi General Hospital set up an investigation to find out and infer the main reasons behind the surprisingly high death rates due to cancer. In their planning phase, the team found two parameters which could be controlled for improvement of the patient care management system. Firstly, the diagnosis delay in the center was detected to be very extensive i.e., 6 months in a lot of cases. The diagnosis time was the time the first cancer suspect was presented to the medical institutions that participated in this study, till the Tumor Board meeting with the final diagnosis. Secondly, treatment delays (3-6 months after the Tumor Board meeting). How OnkoNetwork intervened into the process and suggested effective changes for improvement are shown below (Figure 4):

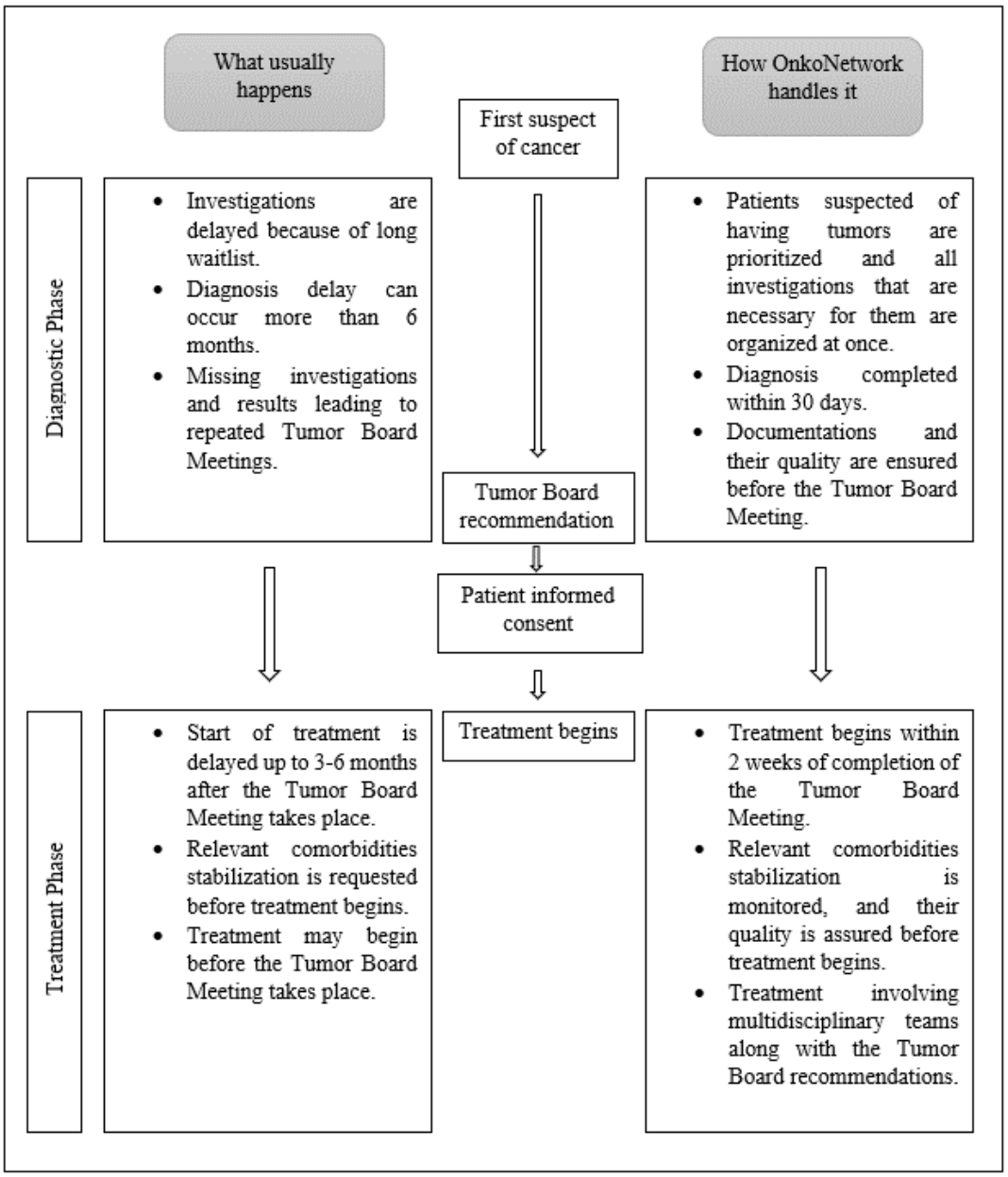

Figure 4: Integration Of Healthcare Service Providers In Onkonetwork (Pitter et al., 2019).

5.3 Characteristics of an Optimal Care Management System

American hospitals and health systems typically consists of infrastructures that are inpatient-focused, a delivery system that is fragmented, incentives that are non-aligned, and cultural barriers that delay efforts for improvements (The Advisory Board Company, 2013). If the institutions were to be restructured to be care management centered, they would be organized quite differently. An ideal care management system both produces and implements

personalized care plans for individual patients, increase access to primary care accessible for everyone, encourage cross-continuum collaboration while the entire organization would run on ubiquitous, actionable data (The Advisory Board Company, 2013). The characteristics of an optimal care management system are shown below (Figure 5):

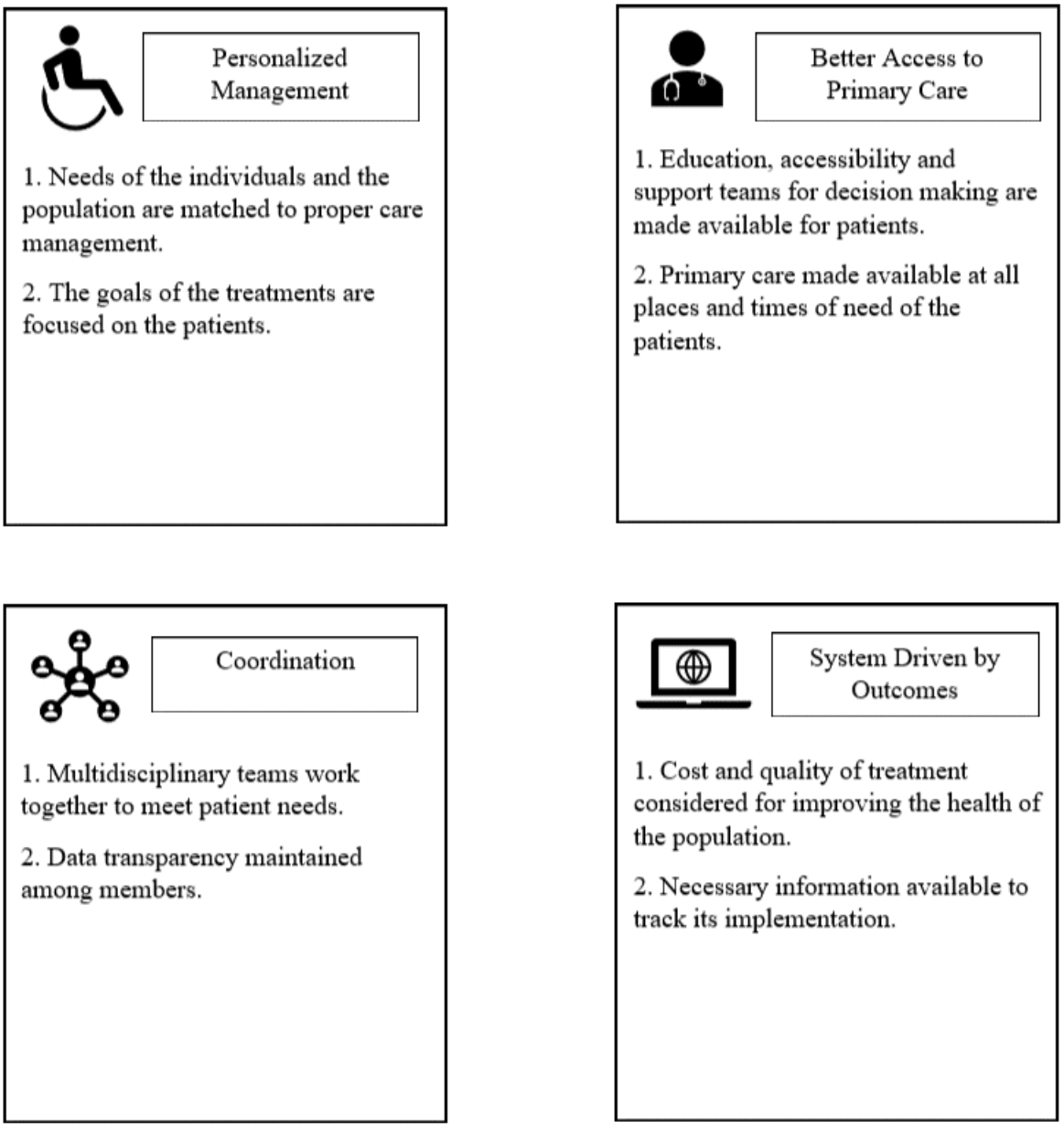

Figure 5: Characteristics of An Optimal Care Management System (The Advisory Board Company, 2013).

5.4 Focusing on High-Risk Patients for the Biggest Care Management Return

According to The Advisory Board Company, targeting high-risk patients leads to quicker and bigger return on care management investments (The Advisory Board Company, 2013). While they encountered many incidences of high-risk care management in their research, all the successful approaches included these three common elements (Figure 6):

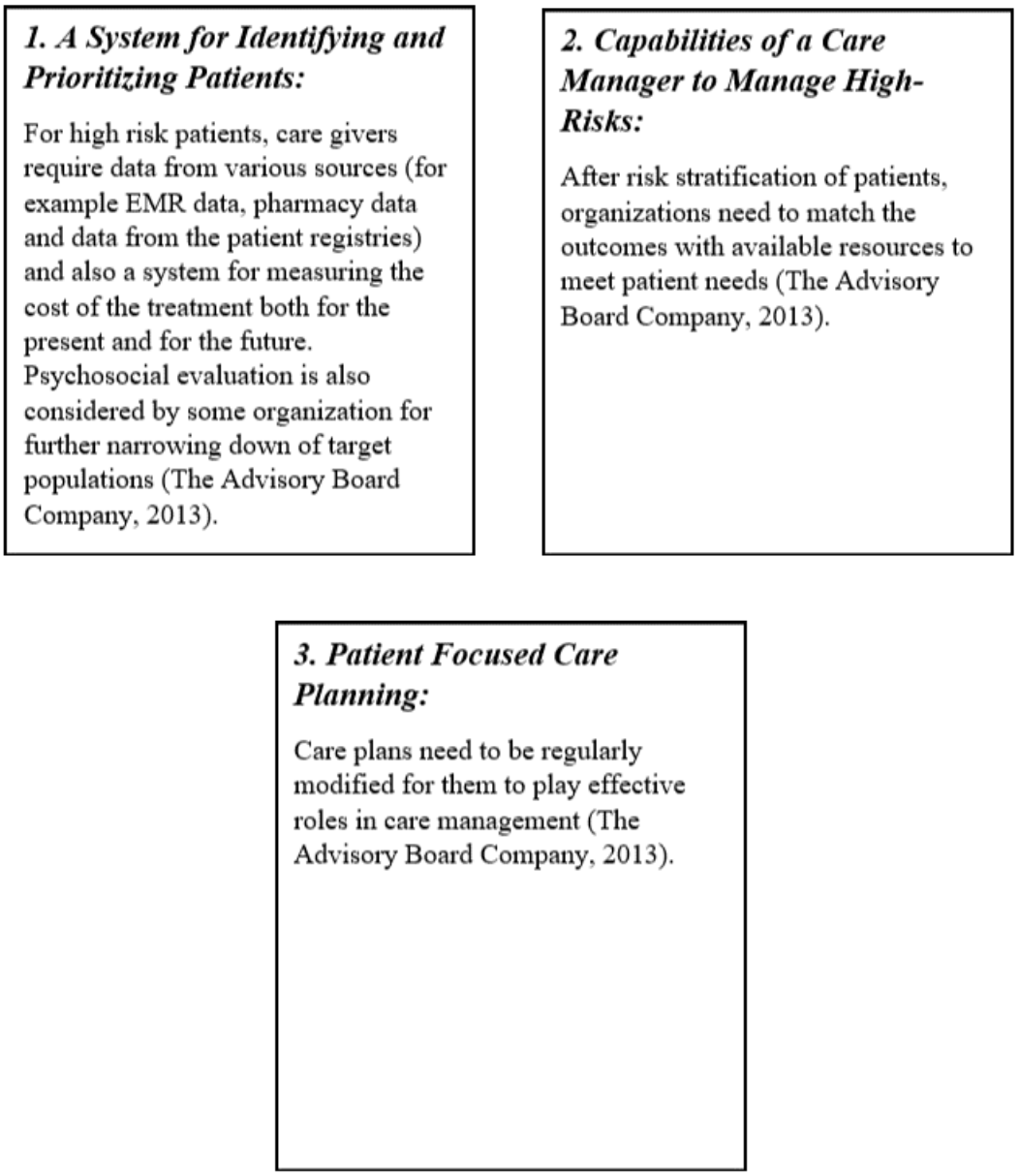

Figure 6: The Three Essential Elements For Successful High-Risk Care Management (The Advisory Board Company, 2013).

Chapter 6

Types of Patient Care Management Systems for Oncology Patients

The landscape of oncological care has been going through expeditious transformation over the years. The evolution and growth of targeted therapy and personalized cancer care have given mankind new reachable goals, even with extremely complex diseases. Development of value measurement for patient care, along with reconstruction of payment and repayment structures for such diseases show how vital it is to ensure continuous development of oncology practice (Burt & Kamal, 2018). Specialty palliative care have already demonstrated higher value, improved patient experiences, and lower costs (Kaufmann & Kamal, 2017).

Oncology is an essential field to consider for further collaborations in patient care. The growing treatment complications from daily new inventions, large expenditures on resources and a growing disease prevalence are the reasons behind it (Kaufmann & Kamal, 2017). The further collaborations can include the different types of patient care management for cancer through psychological care, nursing, palliative and hospice care, improved communication and shared decision making involving the patients themselves, enhanced care coordination among all health care providers and care managers throughout the trajectory of the disease and more patient centered outcomes. Different types of patient care management strategies can be included early into the disease trajectory (for example when the first symptom has been identified by a general physician). Patient care management is not just a set of ground rules for managing patients, it is rather a set of activities involved throughout the disease pathway and beyond, to make the quality of life of the patients and their caregivers better.

6.1 Supportive Care

Supportive care is defined as “the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social or physical need

during their diagnostic treatment or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation and bereavement. In other words, supportive care is anything one does for the patient that is not aimed directly at curing his disease but rather is focused at helping the patient and family get through the illness in the best possible condition." by the Toronto-Bayview Regional Cancer Centre (Hui et al., 2013). Additionally, supportive care also includes activities like managing toxicities caused by cancer treatments and other cancer related complications and providing psychosocial support to the patients and their caregivers (Hui & Bruera, 2016). The ideal structure for supportive, palliative and hospice care is shown below (Figure 7):

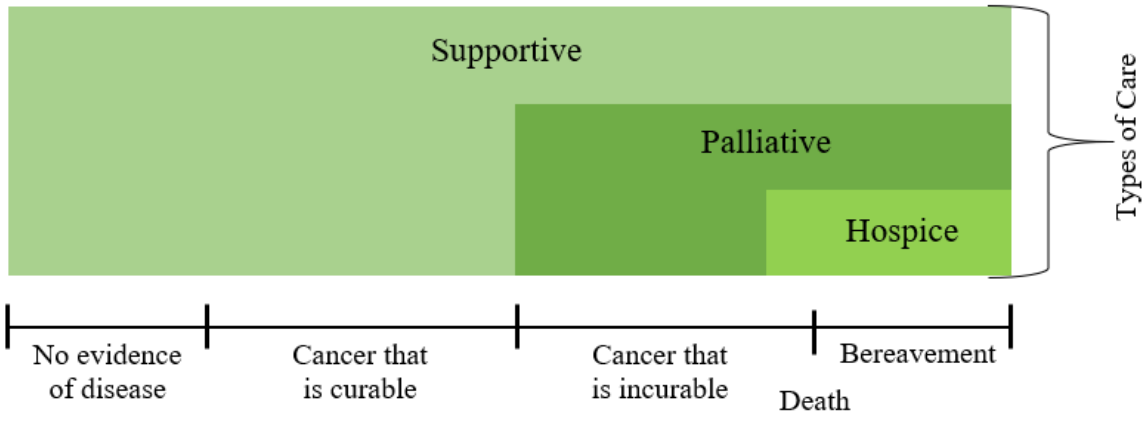

Figure 7: An Ideal Structure For Supportive, Palliative And Hospice Care, According to a Systemic Literature Review (Hui et al., 2013).

As shown above (Figure 7), significant overlaps occur in the objectives and viewpoints of supportive, palliative and hospice care. Hence patient care management of cancer is a holistic approach involving all activities under supportive, palliative and hospice care to ensure better quality of life for the patients. The essential elements of supportive care have been discussed below.

6.1.1 The Treatment Plan

Once cancer has been diagnosed, an organized treatment plan can prove be very helpful. A treatment plan is a type of document describing the pathway to be followed for cancer care, and can be distributed among the patient, family of the patient and/or other care team members to inform and assign responsibilities to them for each portion of the care plan (Balogh et al., 2011). It has been stressed upon by cancer survivors that cancer treatment plan direct patients to navigate the path of uncertainty they face after the confirmatory diagnosis (Balogh et al., 2011).

In a workshop organized by The Institute of Medicine's National Cancer Policy Forum, a participant noted: "Pilots don't take off without a flight pattern, and architects don't break ground without a blueprint. Patients diagnosed with cancer are taking the journey of their life, literally, so the role of the cancer treatment plan in starting a conversation, in promoting comprehension and retention, in managing expectations and anxiety, and providing continuity across settings and episodes is so important." This statement speaks for itself and implies the demand of a treatment plan in the process of patient care management (Balogh et al., 2011). One of the primary goals of patient-focused treatment plan is engaging patients and their care givers in purposeful, in-depth interactions with their health care providers (Balogh et al., 2011). This develops an appropriate treatment plan with all the necessary medical information while also taking the patients' values and priorities into consideration.

Ideally, the components of a treatment plan may include (Balogh et al., 2011):

- Diagnosis type and staging
- Tentative duration of treatment
- Treatment toxicities and their management
- Long term effect of the selected treatment methods

- Responsibilities of the health care professionals and care givers
- Plans for psychological and supportive care
- Monetary issues and their solutions
- Advanced care directions and choices

The main idea of a treatment plan is not only to have a documentation, but to have effective implementation. Once the treatment plans have been implemented timely and effective, better quality of life for cancer patients can be ensured.

6.1.2 Nursing Care

Nurses in the oncology field work in various settings including hospitals for acute services, clinics for ambulatory care, privately operating oncologists' offices, in facilities with radiation therapy, agencies providing healthcare services for home and community (Paula Trahan & Connie Henke, 2003). Their practice includes oncological association with surgery, radiation therapy, gynecology, pediatric and medical oncology. The roles played by oncology nurses extend from the bone-marrow transplantation to community based cancer screening, detection, and prevention (Paula Trahan & Connie Henke, 2003).

Oncology nurses function in nurse-run clinics in the ambulatory settings in a number of ways. They provide cancer care to the patients with long-term follow-up, prescreens patients before the administration of chemotherapy, manages fatigue and other symptoms (Paula Trahan & Connie Henke, 2003). Advanced practice nurses are now playing roles as cancer genetic counsellors as the landscape of cancer genetics continues to grow (Paula Trahan & Connie Henke, 2003). Moreover, oncology nurses are also serving in numerous leadership positions at hospitals and clinics (Paula Trahan & Connie Henke, 2003).The role of the oncology nurse has widespread to assessing patients and educating them, coordinating care, and giving directions

for patient care, for managing symptoms and supportive care (Paula Trahan & Connie Henke, 2003).

A nurse specific palliative care curriculum was developed in the year 2000 in a gathering of nursing educators, practitioners, and researchers (Malloy et al., 2018). The curriculum was reviewed and further developed with six national courses called the train-the-trainer courses that took place from the year 2001 to 2003 was funded by The Robert Wood Johnson Foundation (Malloy et al., 2018). The curriculum was named the End-of-Life Nursing Education Consortium and aimed to satisfy the required nursing care of the patients suffering from serious and complex illnesses at the end of their lives (Malloy et al., 2018).

6.1.3 Palliative Care

Palliative care is a medical branch focusing on the optimization of quality of life (QOL) for patients with severe diseases or conditions. Palliative care involves routine evaluation and management of the eight main domains of care mentioned below (Kaufmann & Kamal, 2017):

I. Physical
II. Social
III. Cultural
IV. Emotional
V. Spiritual
VI. Structural
VII. Psychological and psychiatric
VIII. End of life

Palliative care considers patients and their caregivers altogether and emphasizes on the disease loads, decisional dilemma, and quality of life of the community around a cancer patient (Kaufmann & Kamal, 2017). Palliative care is either simultaneously delivered with curative

care that may be life-long or provided as the primary component of supportive care. Unlike hospice care, palliative care can be integrated at any stage of the illness. Palliative care delivery in oncology follows two models, a primary and a secondary model. Primary palliative care accounts for managing symptoms, making shared decisions, and coordinating psychosocial and community services while ensuring timed oncology care (Kaufmann & Kamal, 2017). Patients with more complicated medical needs demand secondary (also called consultative) palliative care which is provided by a group of specialists for palliative care. Apart from physicians and nurses, the care team may additionally also include counsellors, nutritionists and pharmacists based on the illness type and the care needs of the patient (Kaufmann & Kamal, 2017).

Various randomized trials done previously invariably show notable improvements in quality of life, reduction of symptom prevalence, and improved end of-life care by incorporating specialized palliative care into the standard treatment plan for patients suffering from advanced stage cancer (Kaufmann & Kamal, 2017). Moreover, evidence proves that incorporating palliative care at or around the time of diagnosis for outpatients has proved to be most beneficial. In a recent study with advanced-stage cancer patients showed that every two out of three patients did not have their palliative care needs satisfied (Schenker, Park, Maciasz, & Arnold, 2014). Despite all these eye-openers, oncologists still tend to hold a misconception that palliative care is same as end-of-life care, which often results in late patient referrals to palliative care (Kaufmann & Kamal, 2017).

6.1.3.1 Patient Centered Outcome and Decision Making

Palliative care takes into account multiple Oncology Care Model (OCM) quality measures when it comes to the patient- and caregiver-centered experience (Kaufmann & Kamal, 2017). Managing pain and symptoms, meeting psychological needs, providing patient and caregiver contentment, and prioritizing outcomes reported by patients are important for OCM with

symptom palliation and mental health care being of greatest importance for oncology care (Kaufmann & Kamal, 2017).

Symptom Management: More than half of the patients suffering from incurable cancer experience fatigue, pain and lack of appetite (Kaufmann & Kamal, 2017). Patients with non-metastatic disease have been observed to have a similar symptom burden (Kaufmann & Kamal, 2017). Oncology nurses face daily challenges with the management of symptoms that oncology patients and their families experienced because of the disease or its treatment (Paula Trahan & Connie Henke, 2003). Controlling symptoms has always been a nursing research priority. Fatigue is reported to be the most distressing side effect that nurses have effectively been managing. The Oncology Nursing society (ONS) has been seen to play a huge role in managing cancer associated fatigue by undertaking several actions (Paula Trahan & Connie Henke, 2003).

Psychosocial Needs: Estimations show that 3-4 people out of every 10 cancer patients suffer from various mental health conditions (Kaufmann & Kamal, 2017). A big ratio of advanced stage cancer patients has reported to have unmet spiritual needs. which negatively affects their quality of life (QOL) as well as physical and emotional symptoms (Kaufmann & Kamal, 2017). Psychosocial teams include various discipline such as psychologists, psychiatrists and even child-life counsellors and social workers (Hui & Bruera, 2016).

Medicare's Oncology Care Model (OCM) illustrates the benefits of collaboration of specialty palliative care into the treatment plan for cancer through its quality measures of OCM (Kaufmann & Kamal, 2017). It is believed that most of these measures can be satisfied by incorporating palliative care services early in the treatment process for cancer. One of the four groups of quality measures is —patient- and care giver centered outcomes (Kaufmann &

Kamal, 2017). Table 1 shows the quality domains of this category that are responsible for the palliative care benefit outcomes.

Table 1: Palliative Care Benefits Of The Quality Domains Of Patient And Caregiver-Centered Outcomes (Kaufmann & Kamal, 2017)

Quality domain of patient and caregiver-centered outcomes	**Palliative Care Benefit**
i. **Pain management** **ii. Symptom management**	Ameliorates distress from symptoms, improves quality of life and pain and is responsible for symptom evaluation and treatment.
Mental health requirements	Reduces mental health distress. Raises family bereavement outcomes.
Satisfaction of the patient and caregiver	Improve patient satisfaction. Family, caregiver, social well-being. Emphasizes on cultural aspects of care.
Patient-reported outcomes	Routine screening of patients for compromised mental health condition, symptoms of fatigue and pain and physical function with outcomes tools.

6.1.3.2 Education

Modification to oncology practice and education are necessary due to the evolution of new disease aspects to combat using patient care management strategies. A number of participants attending The Institute of Medicine's National Cancer Policy Forum workshop had opinions that there should be advanced training options for healthcare professionals and care providers with focus on patient-based cancer care planning and highest quality practices in private settings as well as in medical centers (Balogh et al., 2011). Training would be help

professionals become the ideal role model with the aid of feedback systems based on their performance (Balogh et al., 2011).

6.1.3.3 Leadership

In order to promote palliative care worldwide, leaders are being built in addition to educating health care professionals. Several workshops were funded by the Bristol-Myers Squibb Foundation in the years 2014 and 2015 to build palliative care nursing leaders through the program called the Bridging Cancer Care initiative (Malloy et al., 2018) and with further progress, the Hospice Casa Sperantei was established as the Palliative Care Centre of Excellence to provide palliative care in different regions of Europe so that the balance between care and its outcomes can be restored (Malloy et al., 2018).

6.1.3.4 Communication and Shared Decision Making

Discussing the benefits and harms of treatment, and expectations from the treatment is the core of an oncologist's work. Despite this, appropriate and rightly timed discussion about these is hard to attain. Misinterpretation of information becomes very common and frequent reassessments of patients' understanding of the information is required (Epstein, Prigerson, O'Reilly, & Maciejewski, 2016). Outcome expectations of the patients and their families also tend to move away from attainable results as treatment proceeds. Palliative care overcomes challenges concerning communication in oncology care as it explores a patient's understanding of the disease, reviews what the treatment aims to achieve for the future (Kaufmann & Kamal, 2017). A patient's emotions and existential distress are validated by clinicians.

The second category of the quality measures of Medicare's Oncology Care Model (OCM) is — communication and shared decision. Table 2 shows the quality domains of this category that are responsible for the palliative care benefit outcomes.

Table 2: Palliative Care Benefits Of The Quality Domains Of Communication And Shared Decision Making (Kaufmann & Kamal, 2017).

Quality domain of communication and shared decision making	**Palliative Care Benefit**
Exchange of views regarding treatment associated benefits and harms	Elicits aims and preferences that directs the care plan.
Anticipatory guidance	Patient education about the practical knowledge of the illness.
Advance care planning	Strengthens the concept of prognosis. Increases advance care plans. Addresses complex issues associated with severe or incurable diseases.

6.1.3.5 Care coordination among teams

Many oncology patients encounter complex symptoms that needs to be closely followed or extra medical hours for more attention. If these requirements are not met, patients and their families try to obtain emergency care which can otherwise be avoided if the symptoms were managed. This results in higher cost burden and suffering for both the patients and their caregivers (Kaufmann & Kamal, 2017). Palliative care augments care coordination needs within oncological care.

The third category of the quality measures of Medicare's Oncology Care Model (OCM) is care coordination. Table 3 shows the quality domains of this category that are responsible for the palliative care benefit outcomes.

Table 3: Palliative Care Benefits Of The Quality Domains Of Care Coordination (Kaufmann & Kamal, 2017)

Quality domain of care coordination	**Palliative Care Benefit**
Prevent avoidable **i) Emergency department admissions** **ii) Hospital admissions**	Decreased emergency department visits and ICU admissions. Management of symptoms leading to avoidable emergency department visits.
24/7 patient-centered care	Palliative care model is full time, all-inclusive, patient- and family-centered care. Enhances care coordination among patients, care providers and the resources of the community.
Referral to resources of the community	Provides with community resources.
Palliative care referrals	Palliative care referrals increase when the palliative care and oncology meetings among all disciplines takes place.

6.1.3.6 Hospice Care

Hospice care is a type of community-based palliative care based on a community that mainly aims to serve patients and their families near the end-of-life (Hui & Bruera, 2016). Based on the ideal structure mentioned previously, hospice care is a part of palliative care, which in turn is a part of supportive care (Hui & Bruera, 2016). Cancer care tend to swing towards more aggressive treatments at the end of life even though it is not beneficial in terms of patient outcomes. Reports say in every 100 patients suffering from advanced-stage cancer, more than 27 of them are admitted to the intensive care unit in the last month of their lives, whereas 80 of them spend the last 90 days of life in the hospital and both these statistics have been seen to increase over the last 10 years (Teno et al., 2013).

It is evident that delaying shift to care that is comfort focused causes harm (Kaufmann & Kamal, 2017). Delayed hospice referral have shown to result in worsened quality of life (QOL) for both patients and their families (Kaufmann & Kamal, 2017). Reports say cancer patients who die in the hospital have worse physical and emotional distress than those who die at home, and their grieving caregivers have higher chances of experiencing psychiatric illnesses (Kaufmann & Kamal, 2017). An evident survival advantage has been found by enrolling into hospice care rather than other apparent substitutes like late line therapies or early-phase clinical trials in cancers associated to the pancreas or lung (Kaufmann & Kamal, 2017).

The fourth category of the quality measures of Medicare's Oncology Care Model (OCM) is — quality end-of-life care. Table 4 shows the quality domains of this category that leads to the palliative care benefit outcomes.

Table 4: Palliative Care Benefits Of The Quality Domains Of Quality End-of-Life Care(Kaufmann & Kamal, 2017).

Quality domain of quality end-of-life care	**Palliative Care Benefit**
Lower aggressive treatment at the end of life	Reduces chemotherapy administration. Discussions for less aggressive medical care when end of life is near.
Timely and appropriate hospice referral	Enhances early and the number of proper referrals to hospice care. Skillful management of symptoms nearing death.
Reduce emergency department and intensive care unit admissions near end of life	Palliative care lowers the need for intensive care unit admissions and unfavorable interventions. Discussions on lowered intensive care like ventilation and resuscitation. Hospice care lowers emergency department when life is about to end.

Chapter 7

Barriers to Care

The holistic approach to assess and manage quality of life and distress has always been deeply associated with the oncology profession from the very beginning. Barriers to care spur from the very beginning of the disease pathway and tend to prevent attaining a good quality of life for the patients till the very end. A few of such obstacles and limitations to patient care management are mentioned below:

7.1 Diagnostic Delays

Even though cancer is one of the main causes of death in developed and developing countries some cancer types have high likelihood of being cured only if identified early and treated adequately. Set-backs occur all along the pathway of cancer diagnosis and at different levels: patients, primary care and secondary care. More time is taken up when patients fail to identify suspicious cancer symptoms and act on them. The reason behind this could be lack of public awareness of early cancer symptoms (Al-Azri, 2016). It has been found that rightly timed diagnosis of cancer ameliorates survival and quality of life for patients (Neal et al., 2015).

Expedited referrals, proper diagnosis followed by adequate treatment and brief waiting periods before the results of the investigations are declared are highly valued by cancer patients (Vedsted & Olesen, 2015). In a study conducted among Danish cancer patients is showed that they had lower confidence in their general physicians with increasing diagnosis delays (Vedsted & Olesen, 2015). Another study conducted among Danish general physicians in 2010 exhibited that in one out of three cases, they reported compromised quality being closely associated to longer diagnostic periods (Jensen, Nissen, & Vedsted, 2014).

7.2 Financial Affordability

The increasing health-care expenditure in managing cancer has led to further struggle as a consequence of huge financial burden (Azzani, Roslani, & Su, 2015). Evidently a significantly large ratio of the cancer patients suffers from treatment-associated financial harm. With increased medical debt, the downstream effects for some cancer patients can be fatal. A recent study suggests that paramount financial distress and worse mortality are associated (Yousuf Zafar, 2016). The three factors explaining the connection between paramount financial suffering and higher mortality risk are: overall compromised well-being, diminished quality of life in terms of health and inadequate quality of care (Yousuf Zafar, 2016).

7.3 The 'Obvious', 'Difficult' and 'Common' Cancer Symptom Presentations

A finding from the Danish general practice reveals that if general physicians are given the opportunity to simply classify the initial appearance of cancer symptoms, half are classified as alarm symptoms, one-fifth as serious, but specifically not cancerous symptoms and the rest as normal indistinct symptoms (Jensen et al., 2014). Another study finding shows that half of the cancer sufferers in the general practice of United Kingdom did not have any NICE guideline based cancer symptom suspect officially listed in the patient record (Neal et al., 2014) even though symptom presentation occurs in general practice by a group of cancer patients. Hence, it is alarming to say that these symptoms are not considered to be indicating cancer.

7.4 The Challenges of Implementation of Patient-Centered Care Plans

It is believed that patients being insufficiently assertive, their health education and skill and their mental health and cooccurring sickness stand as obstacles for the implementation of patient-centered care planning. Additionally, there exists other limitations from the physicians' side, such as time limitations while explaining complex information, insufficient tools and

infrastructures to assist the treatment plan and insensitiveness to various needs of the patients (Balogh et al., 2011).

Absence of primary care providers' participation in the planning for cancer treatment is a particular coordination challenge as they tend to have better knowledge about the patients and their families than the oncology team because of being acquainted to them for a longer period of time. Having primary care providers alongside during treatment can influence how the team would care for the patients' sufferings (Balogh et al., 2011).

7.5 Challenges of Incorporating Advanced Care Planning in Oncology Care

A number of patient and care provider associated factors influence the complexity to achieve fruitful advanced care planning (ACP) for oncology care. Even though it is very obvious that ACP incorporation is a need and comes with advantages, no premium standard guide for quality, content, approach and care planning timing is (Agarwal & Epstein, 2018). A number of other challenges add to the list when patients are not able to articulate their values and make decision based on enough information about their end-of-life care (Agarwal & Epstein, 2018). These challenges include less understanding of the disease, improper timing and obstacles for communication between doctors and patients (Agarwal & Epstein, 2018).

7.6 The Term "Palliative Care"

A study unveiled a surprising finding that the term 'palliative care' itself has a high probability to be recognized as a barrier as well (Hui & Bruera, 2016). Medical oncologists and mid-level HCPs tend to interpret the term to be the same as hospice or end-of-life care compared to the term 'supportive care' (Hui & Bruera, 2016). This perception has shown to decrease hope and increase sufferings for the patients and their families (Hui & Bruera, 2016).

7.7 Barriers to Optimal Pain Management at the End of Life

Various obstacles lie in the path of optimal pain management near the life-ending phase leading to inadequate control of pain (Gunnarsdottir et al., 2017) (Mayahara, Foreman, Wilbur, Paice, & Fogg, 2015). These obstacles take different forms and can be addressed as 3 main categories of:

- **Patients and their Families:** They tend to have a misconception that pain is a sign of deterioration of the disease and it cannot be reduced as it is a natural part of the illness. Fear also exists that the pain relieving drugs will lead to addiction and abuse (Coyne, Mulvenon, & Paice, 2018).
- **Providers of Health Care:** This includes insufficiently assessing pain either by denying the presence of pain or due to the lack of assessment scale usage for meeting the special needs of the patients (Coyne et al., 2018). The nature of the pain also needs to be recognized by HCPs but sadly it is not taken into account. HCPs also fear tolerance and addiction development to opioids leading to legal issues. Moreover, the opioid prescriber avoids assistance from the palliative care team while prescribing and leaves out other effective non-pharmacological means that can simultaneously act along with the drug to improve pain management.
- **Health Care System:** System imposes restrictions on formularies, limiting access to opioids that are needed for pain management. Treatment cost for both drugs and therapies become a burden with limited insurance facilities. The system also lacks proper specialist education on pain and promptly available palliative resources for severe cases of pain (Coyne et al., 2018).

Chapter 8

Recommendations for Better Patient Care Management of Cancer

Multiple fields in the oncology care has scopes for improvement to be able to deliver the premium quality patient care and patient care management. Even though a lot of breakthrough discoveries are taking place in the field of oncology, the ultimate aim still is to prioritize patient needs, both health wise as well as in terms of quality of life in addition to survival. The recommendations made here do not target any particular group but rather encourages a holistic approach in making patient care experience for cancer patients much better.

8.1 Role of Primary Care in Preventing Diagnosis Delay

Delayed diagnosis is considered a major contributor to the low cancer survival rate in the United Kingdom in comparison with a number of other European countries (Car et al., 2016). One out of every 3 people in the UK has a probability of developing cancer in their lifetime and timed diagnosis has a significant role to play in solving this problem (Car et al., 2016). It has been reported that due to delayed cancer diagnosis, 5 to 10 000 premature lives are lost in England and NHS takes an extra expenditure burden of £ 150 million every year (Car et al., 2016). It has been found that diagnosis of cancer is mostly occurs after symptoms have been presented to the primary care either through screening or after an emergency presentation (Hiom, 2015). So primary care providers here play an extremely important role here. Patients diagnosed with cancer in the primary care are then given referrals to specialists for better diagnostic confirmation and treatment. Diagnostic delays can take place due to issues at the primary care after the symptoms have been presented by the patient till the referral takes place (Car et al., 2016). Being the initial point of contact, the primary care providers contribute a significant role in the pathway of cancer care in United kingdom (Car et al., 2016). As remedies to the problem of delayed diagnosis, primary care providers are expected to actively play roles

in adapting effective strategies that lead to fast detection of early cancer symptoms and follow urgent referral pathways for confirmatory diagnosis.

- Countries that use public funds for health care systems have started using ‘fast-track’ referral pathways for patients highly suspicious of having cancer. This is being implemented due to concerns about diagnostic delays. The biggest implementation of this type of model till date in a country was called the 2-Week Wait Referral System (2WWRS) which was in England in last 10 years period (Emery et al., 2014).
- Symptom epidemiology is a significant element to consider throughout the diagnosis pathway (from first sensation till treatment starts). This decides how the symptom presentation is interpreted by the primary-care providers and the decisions regarding further confirmation and management of the disease are made. An example of a symptom based referral system is the Danish three-legged referral strategy that urgently refers patients with symptoms suspicious of a particular type of (Vedsted & Olesen, 2015). The strategy categorizes the symptoms and show the pathway to referrals in the structural form of a diagnostic funnel (Figure 8).

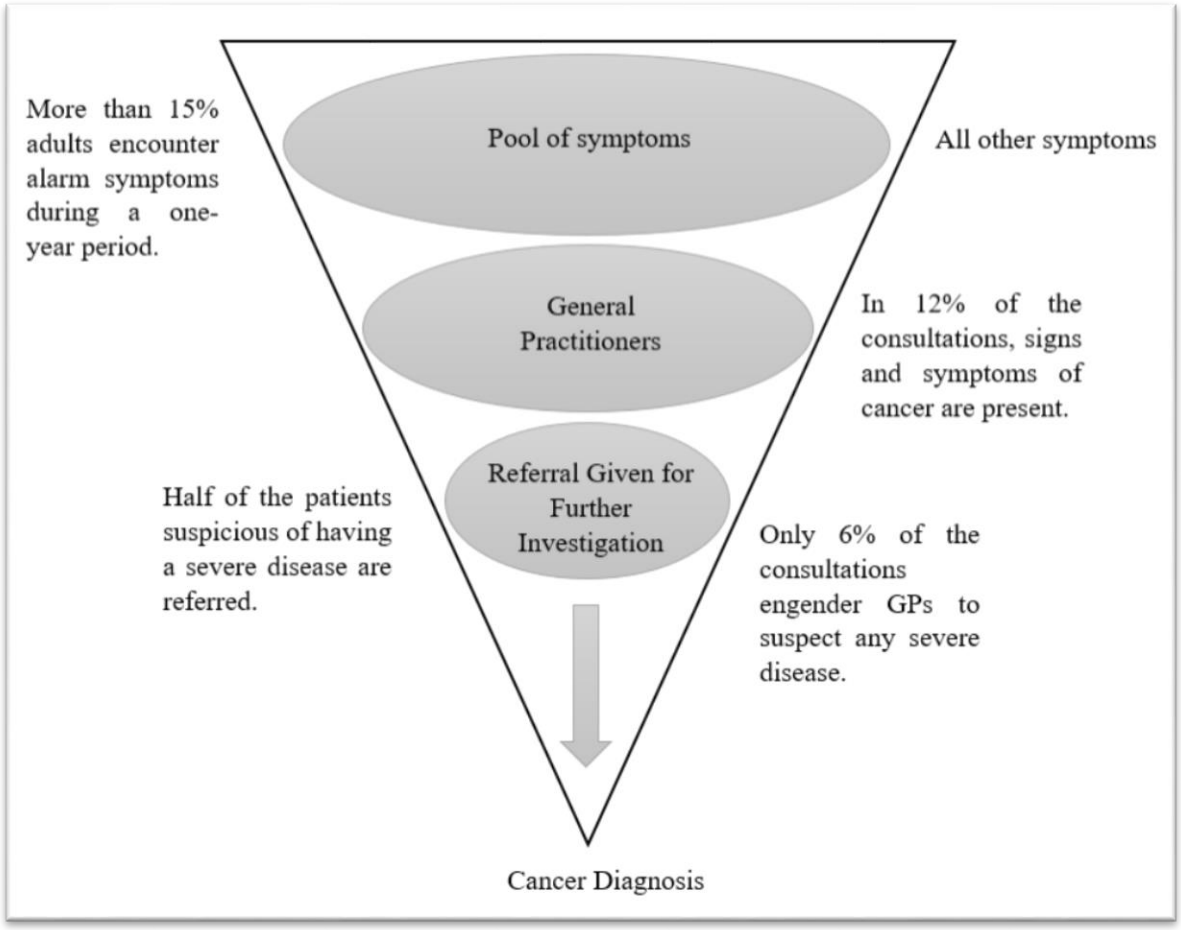

Figure 8: The Structure of the Diagnostic Funnel Representing The Pathway of the Symptoms Leading To Cancer Diagnosis (Vedsted & Olesen, 2015).

Based on the diagnostic funnel, the Danish three-legged diagnostic strategy came up with the following structure (Figure 9):

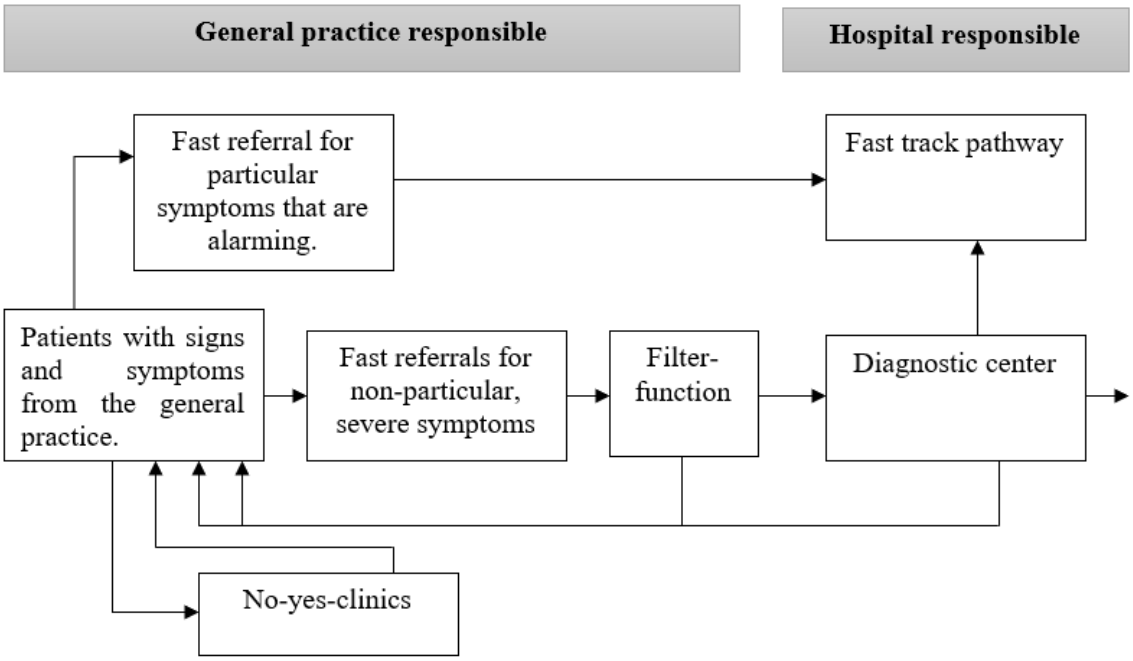

Figure 9: The Diagnostic Structure of the Danish Three-Legged Strategy (Vedsted & Olesen, 2015).

8.2 Reducing Financial Burden

Although studies have associated financial harm with the treatment of cancer, little intervention has been made to solve this issue till now. Long-term answers for such financial problems need to emphasize on changes of policies in an aim to reduce drug prices and come up with advanced insurance models (Yousuf Zafar, 2016). Patients still tend to suffer from high out-of-pocket costs in the treatment process. For speedy solutions, oncologists can emphasize on the value of the care being given, involve patients in discussions on the topic of costs and themselves keep a better knowledge on the availability of the financial resources for the patients (Yousuf Zafar, 2016). Patients also need to have better cost-related knowledge so that they have an idea of the potential costs and resources that are required for the treatment (Yousuf Zafar, 2016). As the record of financial harm due to cancer treatment is growing, it is time that interventions are made to reduce the financial toxicity of cancer care.

Additionally, different health insurance schemes can be made available to cancer patients who tend to suffer and avail treatment for a longer term, as with time the financial burden on the patient and their families only increase. Inclusion of such health insurance plans in the patient care management will play a vital role.

8.3 Strategies to Enhance Communication with Technology

The recent development of informational video tools is giving hope to mitigate obstacles in communication and education for patients. Such videos have proved to act as successful means for ameliorating the communication gap among patients and their physicians in end-of-life care discussions. It brings about a sense of security about their health care decisions and more patients are now picking comfort and relief of symptoms over resuscitation efforts (Agarwal & Epstein, 2018).

8.4 Patient-Centered and Value-Focused Care Models

Models like the Respecting Choices and the Patient-Centered Oncological Care and Choices (POCC) are evident frameworks addressing the multiple factors that contributing to medical decision making (Agarwal & Epstein, 2018). These two models motivate patients to frankly discuss their culture, spirituality, values, hopes and everything that matters to them to be considered for their future health care. The needs and concerns of the caregiver should also be addressed as they play a primary role in supporting and fulfilling patient wishes efforts (Agarwal & Epstein, 2018).

8.5 Oncological Palliative Care

A lot of scopes of improvement lie in the field of oncological palliative care. A few of them have been addressed below:

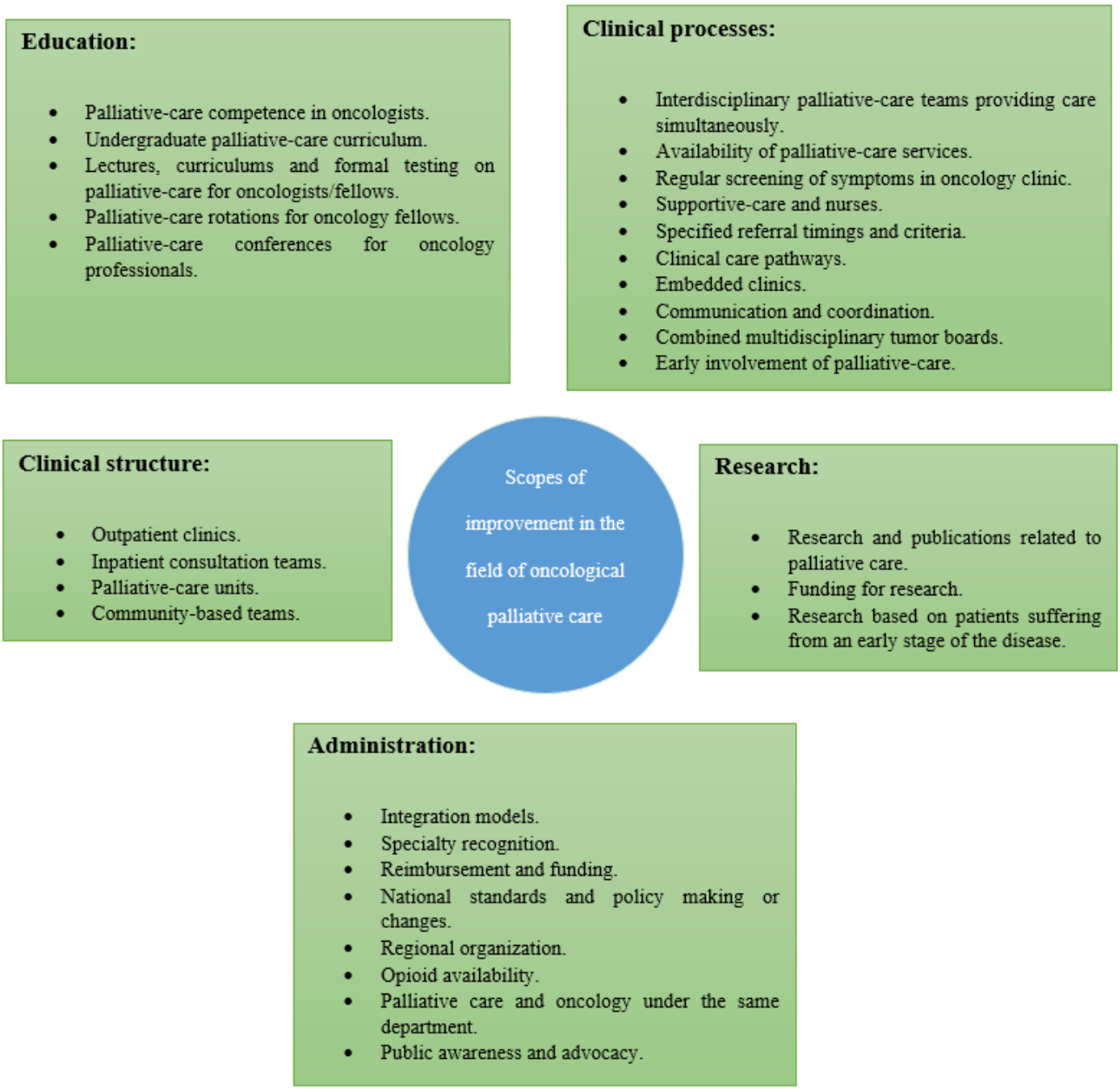

Figure 10: Recommendations For Improvement In The Field Of Oncological Palliative Care (Hui & Bruera, 2016)

Chapter 9

Case Study on Current Cancer Scenario in Bangladesh

Bangladesh, currently at 168 million people, is the eighth most populous country in the world (World Population Review, 2019). In a report World Health Organization (WHO) claimed that there were 150,781 new cancer cases in Bangladesh in 2018 with 12,764 cases accounting for breast cancer which comprises of 8.5% of all the cancer patients (Dhaka Tribune, 2019). Breast cancer has been identified as the highest single cancer category for women accounting for 19% of all women cancer patients (Dhaka Tribune, 2019). The report also mentioned that there were 83,715 male and 67,066 female cancer patients in 2018 around the country (Dhaka Tribune, 2019).

The estimated number of cancer patients are reportedly increasing day by day and currently there are over 1.5 million cancer patients in Bangladesh, according to WHO's most updated estimation (Dhaka Tribune, 2019). It also estimates that every year around 200,000 people are attacked by cancer while 150,000 people die of the disease (Dhaka Tribune, 2019).

According to the Cancer Awareness Foundation Bangladesh, the country at present has 37 cancer treatment facilities. National Institute of Cancer Research Hospital (NICRH) Director Prof Dr Md Mosharraf Hossen told the Dhaka Tribune in an interview that everyday about 1,200 cancer patients visit the cancer hospital for treatment, of which 550 patients are given radiotherapy and 275 patients are given chemotherapy. He also mentioned about the burden of cancer treatment cost and said that NICRH tries to provide free medicine to about 50-60% of their cancer patients to reduce this burden (Dhaka Tribune, 2019).

According to 2013 reports, there were around 150 qualified clinical oncologists and 16 pediatric oncologists all over the country. Regular cancer treatments were made available in 19 hospitals (Hussain, 2013). Bangladesh developed a unique National Cancer Control Strategy and Plan of Action for the term 2009-2015 which was formulated with the help of the World Health Organization (WHO). The objective behind this was to develop and put into effect the continuum of cancer care through comprehensive control of cancer (Hussain, 2013).

The National Control Strategy and Plan of Action 2009-15 mentions early detection and palliative care as parts of the strategy (Hussain, 2013). For early detection, it talks about awareness campaigns for early symptom identification and emphasizes on the screening of cervical and breast cancer. In case of palliative care, the strategy says that palliative care should be made into an integral part of cancer management and talks about plans for ensuring morphine availability for better pain management (Hussain, 2013).

On the contrary, according to the WHO country profile of Bangladesh of 2014, it has been seen that no screening facilities for cervical cancer, breast cancer and colorectal cancer were accessible at the public primary health care (World Health Organization (WHO), 2014). Chemotherapy and radiotherapy were generally available in the public health system, but oral morphine was unavailable (World Health Organization (WHO), 2014). Additionally, community or home care for patients suffering from advanced stage cancer were also generally unavailable in the public health system (World Health Organization (WHO), 2014).

9.1 Cancer Burden in Bangladesh

Cancer burden in Bangladesh is variable among genders and age groups. Although Bangladesh has no population-based cancer registry, a total of 150 781 new cases of cancer were reported among all gender and ages in 2018 (World Health Organization (WHO), 2019a). Among these, the most reported type of cancer was esophageal cancer (13.9%) followed by lip & cancer of

the oral cavity (8.9%), breast cancer (8.5%), lung cancer (8.2%) and cancer of the cervix & uteri (5.4%) (World Health Organization (WHO), 2019a). The most prevalent types of new cancer cases among both genders in 2018 in Bangladesh have been illustrated below (Figure 11 – Figure 18):

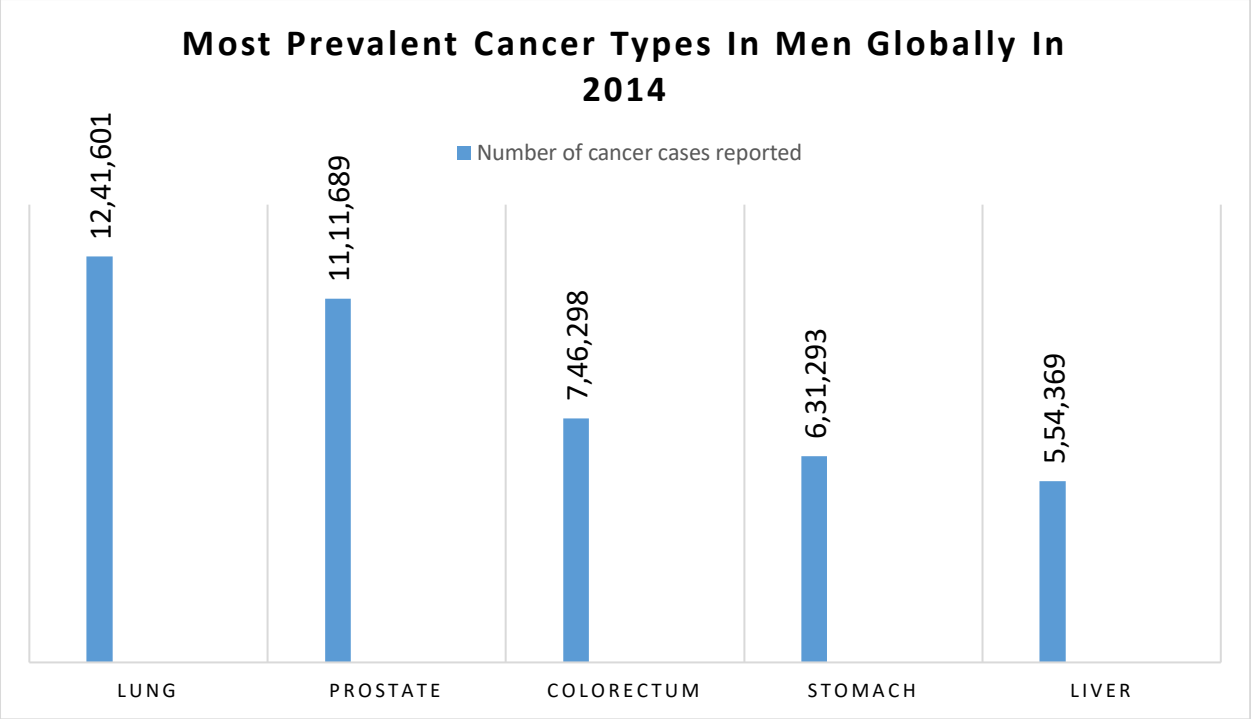

Figure 11: Most Prevalent Cancer Types In Men Globally In 2014 (World Health Organization (WHO), 2014)

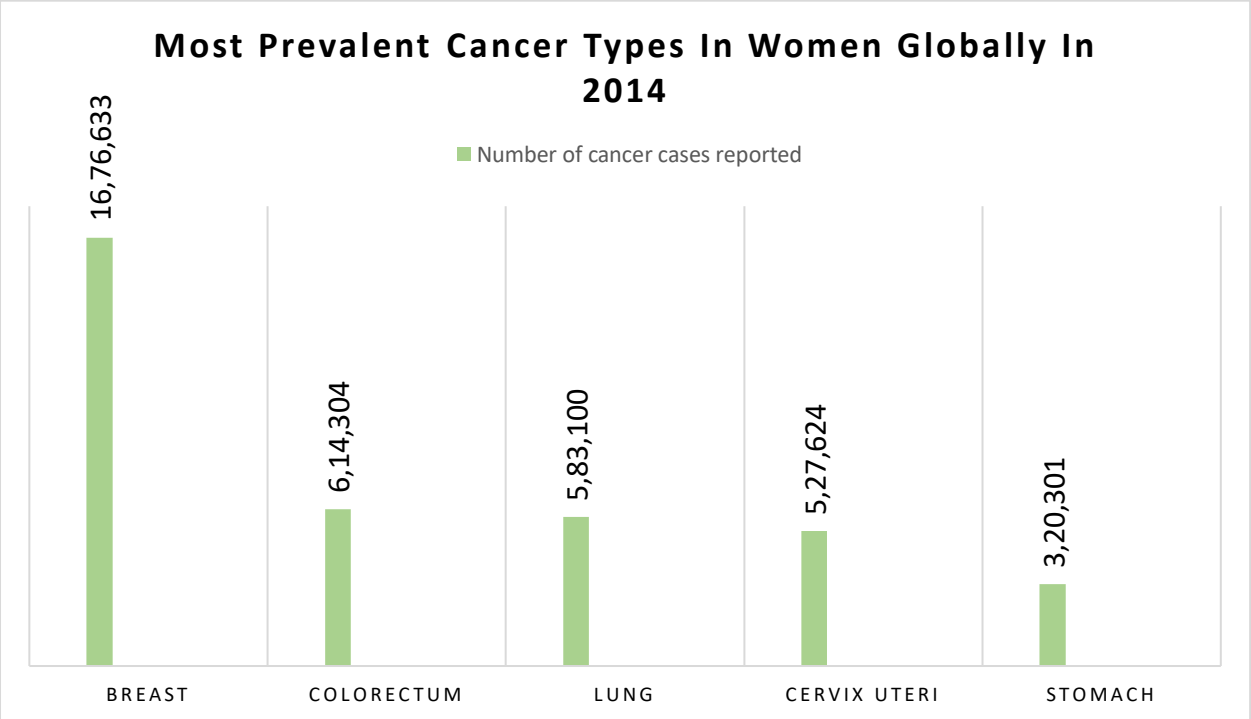

Figure 12: Most Prevalent Cancer Types In Women Globally In 2014 (World Health Organization (WHO), 2014)

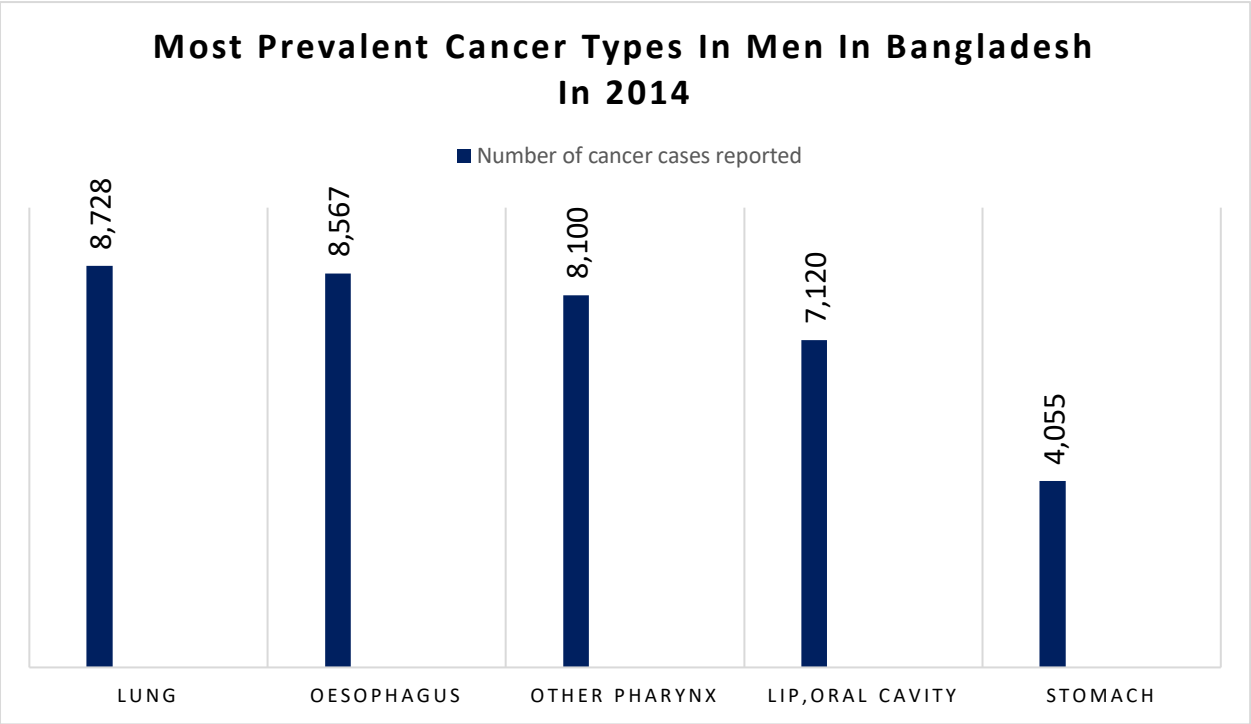

Figure 13: Most Prevalent Cancer Types In Men In Bangladesh In 2014 (World Health Organization (WHO), 2014)

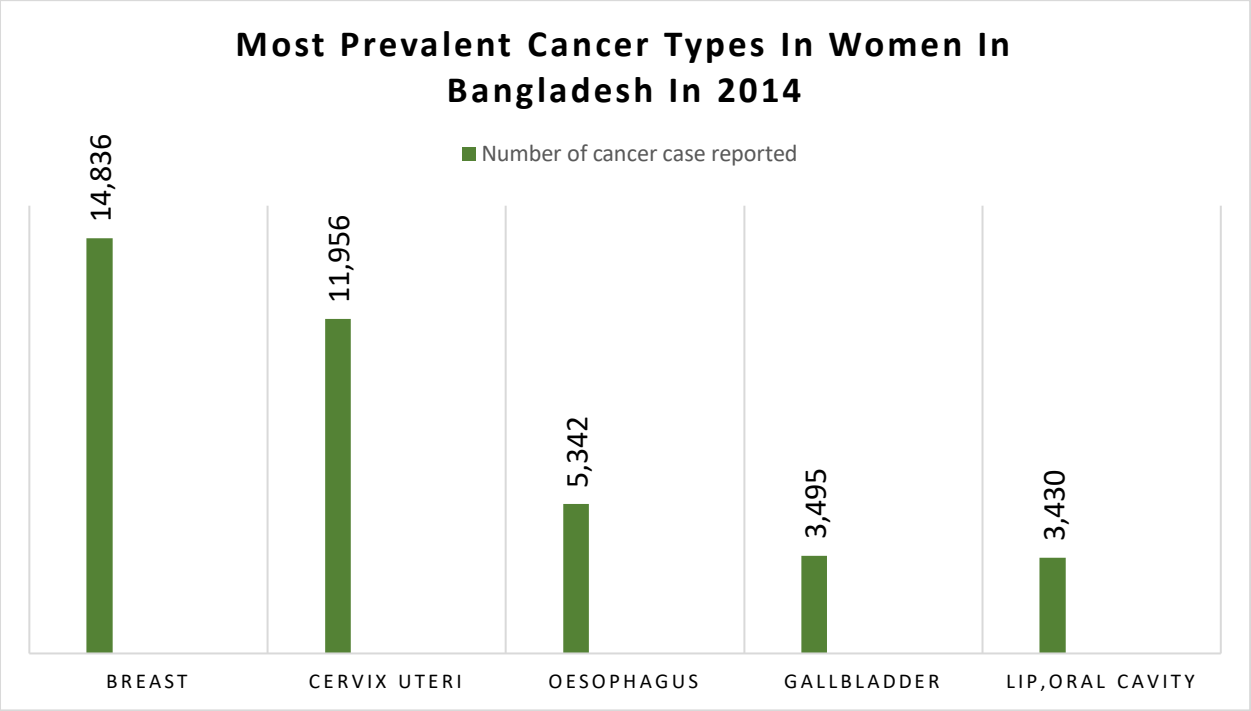

Figure 14: Most Prevalent Cancer Types In Women In Bangladesh In 2014 (World Health Organization (WHO), 2014)

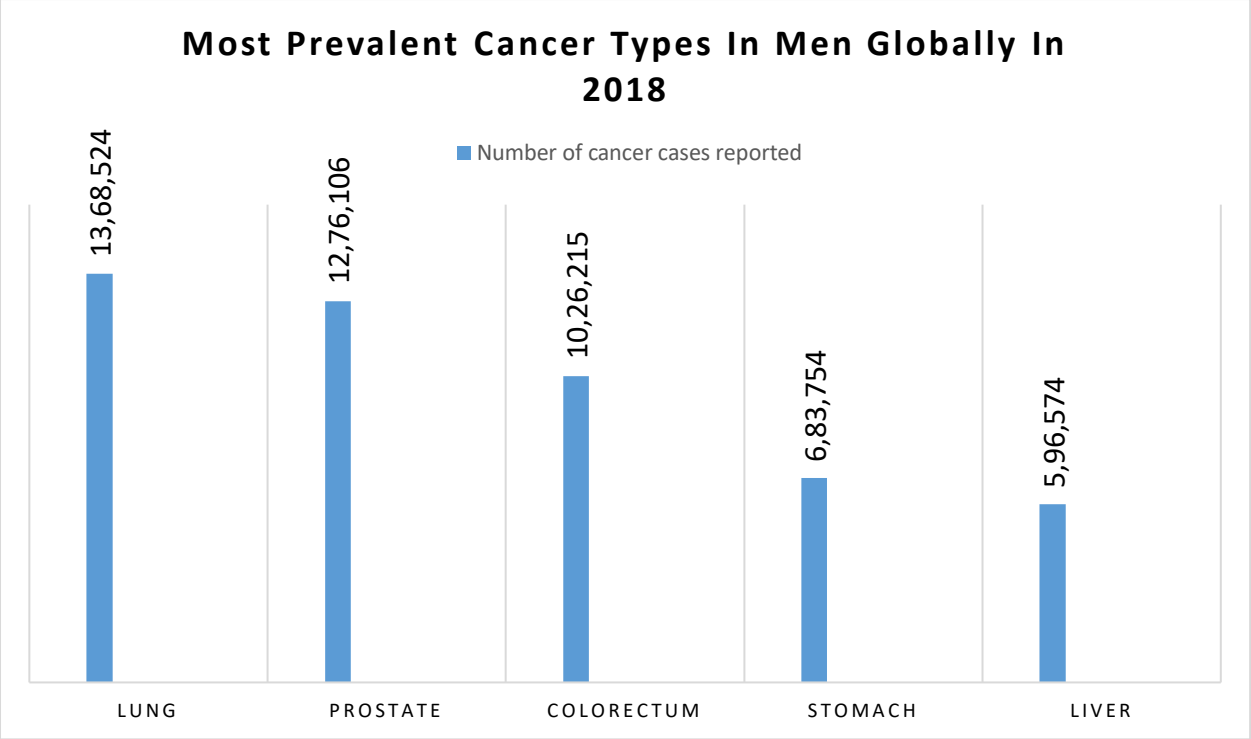

Figure 15: Most Prevalent Cancer Types in Men Globally In 2018 (World Health Organization (WHO), 2018)

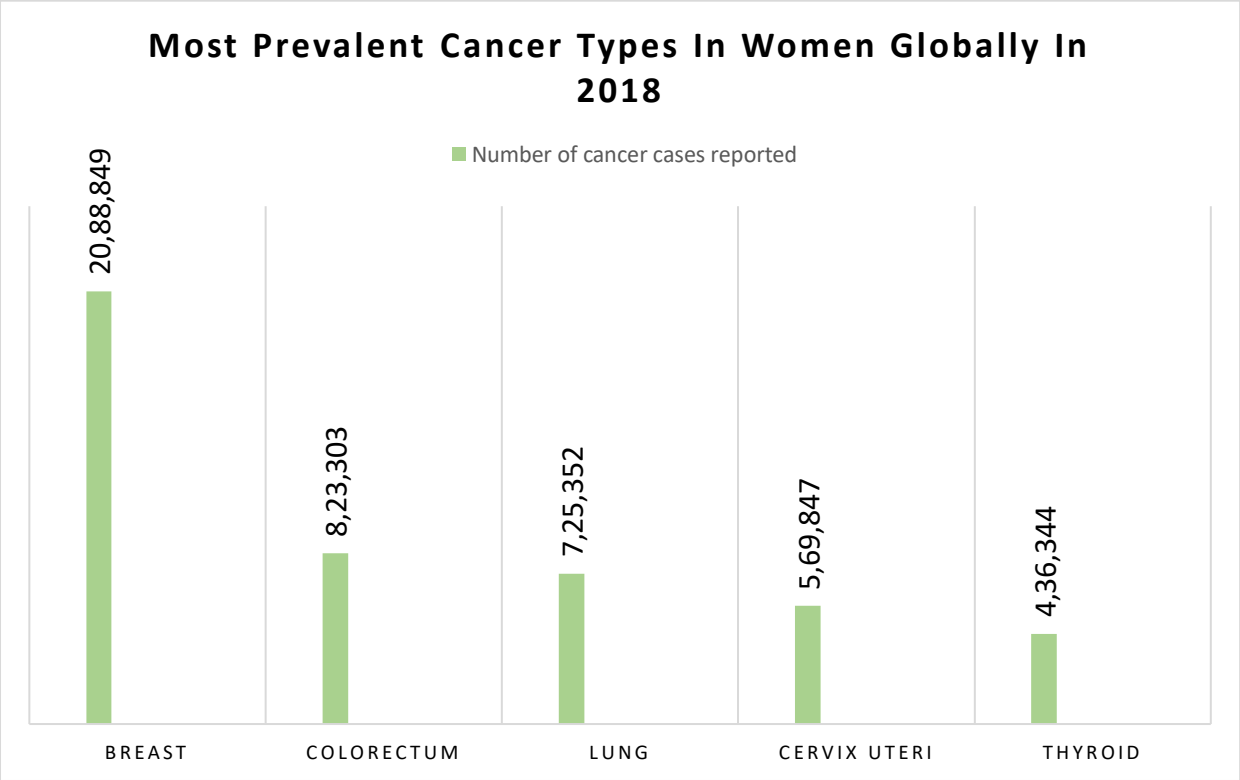

Figure 16: Most Prevalent Cancer Types In Women Globally In 2018 (World Health Organization (WHO), 2018)

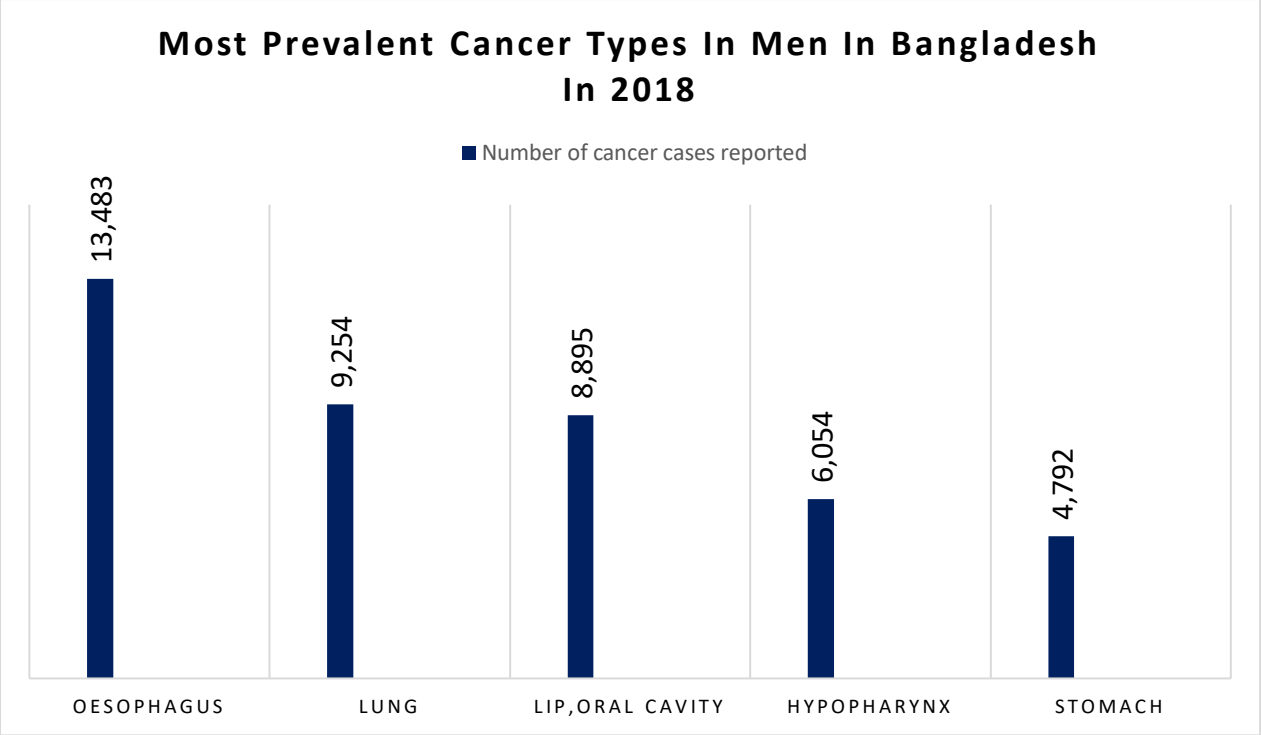

Figure 17: Most Prevalent Cancer Types In Men In Bangladesh In 2018 (World Health Organization (WHO), 2018)

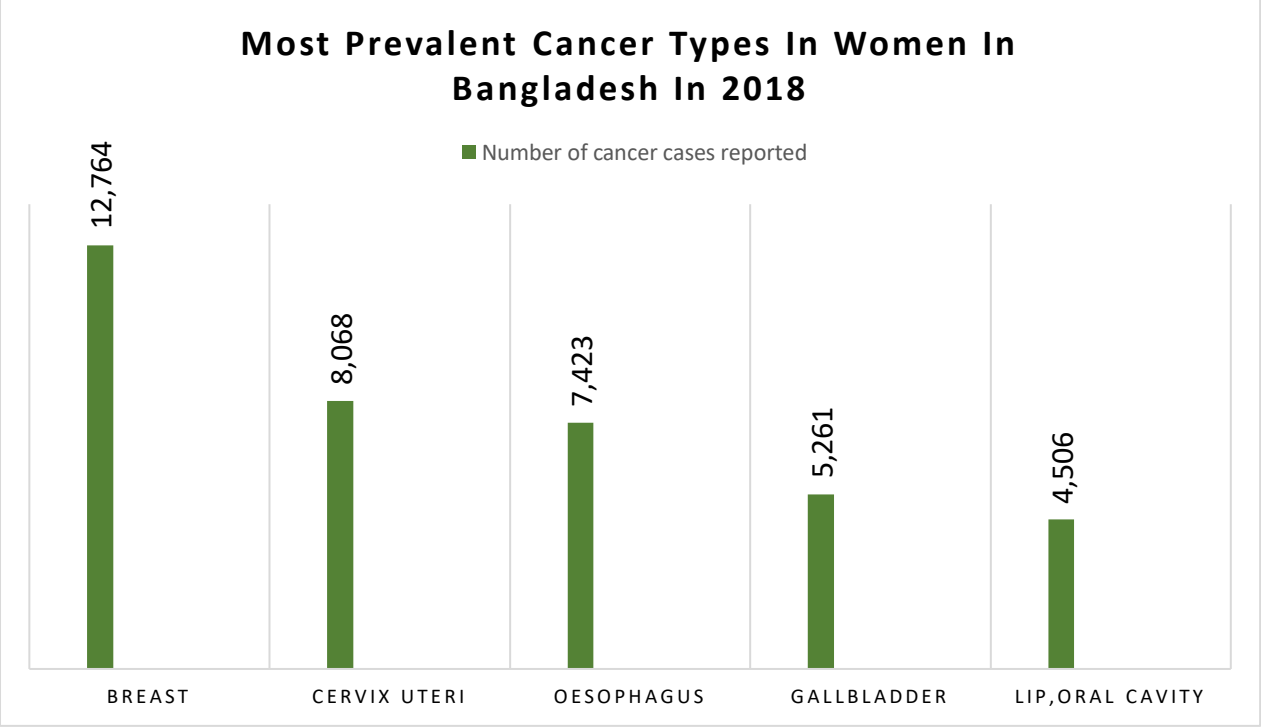

Figure 18: Most Prevalent Cancer Types In Women In Bangladesh In 2018 (World Health Organization (WHO), 2018)

Bangladesh has an economically productive population of 66.1 million people between the age group of 30 to 69 years, who makes up 40% of the entire population of the country (World Health Organization (WHO), 2018). Approximately 77% of the cancer patients visiting NICRH in 2016 belonged to the working age population (15 to 64 years), which itself is an extremely alarming piece of information. According to the National Institute of Cancer Research & Hospital (NICRH), which is the country's only tertiary level government hospital, majority of the cancer patients visiting the hospital were from the age group of 45-54 years (31.1%). The second leading age-group was 55-64 years (16.0%) (DGHS, 2017).

Additionally, the cancer mortality rate in Bangladesh in 2008 was 1,50,000 people per year (DGHS, 2008) which rose to 8,86,000 people in 2014 according to the WHO country profile for Bangladesh (World Health Organization (WHO), 2014). Just like many other countries in the world, Bangladesh also has an increasing prevalence of cancer. The cancer registry data of NICRH and BSMMU previously have revealed that 68% of the cancers in the male and 5% of the cancers in female were associated with tobacco intake (DGHS, 2008). So it can be said that it is absolutely avoidable. The most common cancers caused by tobacco are found to be lung cancer, larynx cancer, urinary bladder cancer, and esophageal cancer and pharyngeal cancer all due to smoking tobacco (DGHS, 2008). Cancers associated with parts of the mouth are due to chewing and smoking tobacco (DGHS, 2008). Since women in Bangladesh are less likely to be smokers due to socio-cultural reasons, tobacco related cancer in female is observed to be still low (DGHS, 2008). Currently overall 37.8 million adults in Bangladesh use tobacco, of which 46% are male while 25.2% are female (World Health Organization (WHO), 2017). The detailed data outcome from the Global Adult Tobacco Survey done for Bangladesh in 2017 is shown below in Table 5.

Table 5: Global Adult Tobacco Survey Data For Bangladesh In 2017 (World Health Organization (WHO), 2017)

Population	**Type of Tobacco use**	**% of Male Population**	**% of Female Population**
37.8 million adults	Currently use tobacco	46	25.2
19.2 million adults	Currently smoke tobacco	36.2	0.8
15.0 million adults	Currently smoke cigarettes	28.7	0.2
5.3 million adults	Currently smoke bidis	9.7	0.6
22.0 million adults	Currently use smokeless tobacco	16.2	24.8
20.0 million adults	Currently use betel quid with tobacco	14.3	23.0
3.9 million adults	Currently use gul	3.1	4.1

In a study done by WHO previously (World Health Organization (WHO) & WHO Regional Office for South East Asia, 2007) reporting the effect of tobacco-related illness in Bangladesh, estimates showed that there were 49,000 oral cancer, 71,000 laryngeal cancer and 196,000 lung cancer cases in Bangladesh for people of age 30 years or more (DGHS, 2008). In a recent study done by WHO, it showed that tobacco kills 1,61,253 people in the world every year (World Health Organization (WHO), 2018). Cancer is the third most prevalent way in which tobacco kills consisting of 20% of the deaths (World Health Organization (WHO), 2018). Hence it can be said that 32, 250 cancer associated deaths can be prevented every year by avoiding tobacco use in the population.

9.2 Economic Impact of Cancer

As mentioned earlier, 77% of the cancer patients belong to the main workforce structure of Bangladesh causing a huge economic impact both in terms of direct and indirect cost. A WHO

study previously revealed that the yearly cost of tobacco-associated illnesses in Bangladesh is approximately to be 45 billion taka taking into consideration that only 25% of the patients with tobacco-associated illnesses were given hospital services (DGHS, 2008). On the other hand, the total yearly gain from tobacco sector is approximately 24.8 billion taka that is taken by the government (DGHS, 2008). Thus the cost of tobacco consumption to the country exceeds the gain from the revenue and wages by 20.3 billion taka every year (equal to US$ 344 million) (DGHS, 2008). This shows that other than the ethical point of view, the economy of Bangladesh would greatly gain from cutting down tobacco consumption.

Chapter 10

Conclusion

While death and dying will always be a part of life, efforts should be made to reduce the sufferings of death as much as possible. This is exactly where patient care management plays a vital role in oncology care by laying hands on various fields of care and involving various professionals to play their significant part in the trajectory of the disease. Accepting this care as a fundamental human right for everyone, regardless of their race and financial status, health care professionals should keep on educating themselves to providing the best quality of life for the patients as well as promote it.

Successful and cost-effective strategies can be made and implemented in early diagnosis, screening, treatment, and palliative care to reduce sufferings near the life ending phase of cancer patients. Despite numerous treatment options, the patients' preference and decision should be a priority. Cancer management can be quite complicated and requires proper strategies to ensure highest quality of individualized care being delivered on time for the patients. Proper planning and targets need to be designed and set to increase the competitiveness among healthcare providers along with improving overall care and services for the cancer patients.

Just as health care professionals witness birth, they also have the privilege of spending the sacred concluding hours with the patients and their families. This gives them a remarkable opportunity to ensure quality of the end-of-life care with minimal sufferings for both the patients and their families.

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