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# Evaluation of Colorectal Cancer Management in the Gaza Strip

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## Evaluation of Colorectal Cancer Management in the Gaza Strip

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**Thesis Approval** 

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#### 1440/2019

### Dedication

Every challenging work needs self-efforts as well as guidance of those who were very close to our heart. My humble effort I dedicate to my sweet and loving father and mother who always give me an endless source of power and encouragement.

To my wonderful lovely husband Mohammed for his endless support, he is a continuous source of support, hope and motivation.

To my brothers and sisters, Abdallah, Siraj, Diana, Nermeen and Areej; thanks for always being there for me.

To my lovely daughters Aseel and Daliah who are the bright of my today and future. To the family of my husband.

Never forgotten my uncle Fathi and my mother in law Fatima, who died from the cruel colorectal cancer disease.

To every teacher taught me in the school, in the faculty of medicine and in the public health college for their efforts.

To all my friends especially Mai, Asmaa, Haifa and Esraa for their endless support and my colleagues in the work.

To everyone who helped me to finish this study.

Dalia T. El-Wehedi

### Declaration

I certify that this thesis submitted for the degree of Master, is the result of my own research, except where otherwise acknowledged, and that this study (or any part of the same) has not be submitted for a higher degree to any other university or institution.

Signed: .....

Dalia Talaat El-Wehedi

Date:

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### Abstract

Colorectal cancer (CRC) is the leading cancer among men in Gaza Strip (GS) and it is considered the second common cancer after breast cancer for both sexes combined. The evaluation of the services and facilities used for the management of colorectal cancer is essential for monitoring the health care system effectiveness in managing and preventing CRC. This is a triangulated study was conducted to evaluate the services that are provided to CRC patients who were diagnosed in the period 2016-2017. The study is a triangulated study, which is composed of both quantitative and qualitative components. The quantitative data was represented by cross sectional study by using four checklists that identified the number of the available beds and rooms for patients, available health care human resources, diagnostic equipment and exploring the completeness of cancer patients' medical files. For the qualitative data, it included interviews with key informants as well focus groups with colorectal cancer patients.

The results of the study showed that there are shortages in the health care staff and weakness of training, inappropriate infrastructure of oncology buildings, rooms and beds and deficiencies in necessary equipment and supplies. Moreover, the prevention and screening services for colorectal cancer are totally absent in MOH strategies. In addition, colorectal cancer diagnostic services are facing many barriers that lead to the delay in the diagnosis of the disease. There are obvious shortages in some facilities, which are necessary for diagnosis as fecal occult blood tests, colonoscopies, tumor marker test, Gamma Camera, Linear accelerator, MRI and CT scanners, augmented by poor awareness of patients, physician and health system role. Treatment of colorectal cancer disease faces many obstacles that decrease the quality of care such as frequent unpredictable shortage in the essential chemotherapy medications, lack of oncology specialized surgical human resources and the absence of radiotherapy treatment. This is joined by the absence of palliative care and poor psychological support to the colorectal cancer patients and their families.

The information system, which is represented by cancer registry, research and colorectal cancer patients' medical files show a lot of gaps and serious defects that affect the quality of the provided services to colorectal cancer patients. All the gaps and weaknesses in the provided care are accompanied by the deep dissatisfaction of the colorectal cancer patients.

The weaknesses and gaps in the strategy and services used for colorectal cancer management in Gaza Strip include the administrative planning to implementation issues. The gaps are related to political, financial and administrative issues that are reflected on the quality of the service provided to the CRC patients.

The study recommends the enhancement of prevention and screening programs for colorectal cancer disease, improving the contact between the variable sectors providing the management care of colorectal cancer disease, providing all the needed infrastructures and essential medications used in the management of the colorectal cancer patients. Also starting a comprehensive psychological care for the colorectal cancer patients and improving the contact between the health care provider and the colorectal cancer patients and finally starting a deep provision of the information system that represented by establishing auditing system for the medical files, improving the cancer registry system and enhancing the research.

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### List of Abbreviation

ACSAmerican Cancer SocietyASGEAmerican Society for Gastrointestinal EndoscopyBMIBody Mass IndexCA 19-90Carbohydrate Antigen 19-9CEACaroinoma Embryonic AntigenCIConfidence IntervalCRCColorectal cancerCRAMerrican Society for Gastrointestinal Endoscopy J/IIFRAGE I/IIFeacha Coccult Blood testFOBFeach Occult Blood testFSGeneral PractitionersGRSGeneral PractitionersGRAInternational SystemTGDJactandal Atomic Energy AgencyFISMisity Of HealthFAGAMagnetic Resonance ImagingMARIMajnetic Resonance ImagingFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDSociety Control ProgramFNGDMaional Cancer Control ProgramFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDSociety Control ProgramFNGDMaional Cancer Control ProgramFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGDNon-Communicable DiseasesFNGD	AC	Adjuvant chemotherapy
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OECDOrganization for Economic Cooperation and DevelopmentOROdd's Ratio	NCD	Non- Communicable Diseases
OR Odd's Ratio	NGOs	Non-Governmental Organizations
	OECD	Organization for Economic Cooperation and Development
PA Physical activity	OR	Odd's Ratio
<b>I</b> A Thysical activity	РА	Physical activity

PCO	Patient Centered Outcome
PCRF	Palestine Children's Relief Fund
PCSB	Palestinian Central Bureau of Statistics
PET scan	Positron Emission Tomography scan
RCR	Royal College of Radiologists
SPSS	Statistical Package for Social Science
UNRWA	United Nations Relief and Work Agency for Palestine Refugees
US	Ultrasound
USAID	United States Agency of International Development
WHO	World Health Organization

### Chapter One Introduction

#### 1.1 Overview

Cancer is a terrifying generic name that can affect anyone in any time in any part of the body, which is unfortunately considered nowadays the major cause of morbidity and mortality worldwide. There are 8.8 million deaths yearly from all types of cancer worldwide, which represents one of each six deaths (WHO, 2015). Colorectal Cancer (CRC) is considered the third most common cancer and the fourth leading cause of cancer related deaths worldwide (Favoriti et al., 2016). The CRC incidence and mortality rates vary according the country developmental index, as in low income countries the incidence and mortality rates increasing rapidly and decreasing or stabilizing rates in high income countries, in 2030 the CRC cases worldwide will increased by 60% to more than 2.2 million new cases and 1.1 million deaths (Arnold et al., 2016). The early diagnosis and treatment of CRC will increase the chances for survival, as being late in diagnosing or controlling the CRC will result in the progression of cancer and finally to disability and death (WHO, 2017<sup>a</sup>).

In Palestine, the burden of cancer in the mortality rate is large, as it constitutes the second major cause of death after the cardiovascular diseases. Colorectal cancer is considered the second cause of cancer related deaths after breast cancer in both sexes, which shows that there is an observed increment in the incidence of CRC as the second most common cancer after the lung cancer in males is the CRC (Ministry of Health, 2015). As recently, Ministry of Health (MOH) reported the CRC as the leading cancer in males, which represents 15.5% of all male cancers.

Worldwide variation in colorectal cancer incidence and outcomes may be due in part to the disparities in access to health care and services. Any defect in the health care system can prevent the optimal care at any point on the patient's pathway has the potential to have an adverse impact on patient outcomes (New Zealand Ministry of Health, 2011). For that, the management of colorectal cancer should be a multidisciplinary approach involving all the health system components, and should be guided by a precise staging and histopathology. For this reason, all CRC patients should be effectively treated by a team consisting of pathologists, radiologists, surgeons, oncologists, and colorectal nurse specialists (Leslie & Steele, 2002).

#### **1.2 Research problem**

Personal communication with the Palestinian Health Information Centre (PHIC) represent that the incidence of CRC in males was the first of all cancer types; during 2015-2016, 230 cases were reported with incidence rate of 12.0/100.000 male population. For females, CRC is the second most common cancer after breast cancer, where 210 cases are reported with incidence rate of 10.2/100.000. Although there is an increment in the number of cases of CRC in both genders, there is still non-unified, not clear, fragmented MOH health system facing many challenges against its stability that cannot meet this marked increment. All of this reflected by the absence of vital services for the management of CRC including most types of (chemotherapy, radiotherapy, Positron emission tomography (PET) scan, complicated surgeries and palliative treatment).

The problem is enhanced by the current social problems, poor economic status, political division and poor referral system with long waiting lists and decreased the number of referral decisions by MOH in Gaza less than 80% of the suspected every month (WHO, 2017<sup>b</sup>). Unfortunately, there is no clear protocol or management plan for managing CRC patients, with no previous studies done on the evaluation for the services provided for managing CRC patients, only for risk factors and survival analysis for CRC. For that, it is essential to review the available management strategies and services for CRC in the Gaza Strip (GS) to provide a high quality of services for CRC patients, as they deserve it.

This study will be the first study to review the available strategies and provided services for management of CRC in order to provide baseline for future improvement to enhance the quality of life for CRC patients.

#### 1.3. Justification of research:

Revision of the available strategies and the provided services to CRC patients and comparing it to the international modalities used in the management of CRC which will reflect the efficiency and effectiveness of the health care system. This study is the first of its kind in Palestine thus, the research will add to the body of knowledge in one of the most important parts in social sciences, therefore it will bring great benefit to the society, government and the community. As CRC disease is hard to be cured completely if diagnosed lately and because of the current political situation in Gaza Strip which characterized by siege, shortage of a lot of essential drugs and limited resources and limited research. A miracle should be done to those patients to enhance their quality of life and to preserve their dignity in gaining treatment as they had the right to survive.

Moreover, in order to enjoy a good health we need a strong CRC management program that will protect, detect early CRC cases in general population, manage and promote high quality social, physical, psychological wellbeing of all CRC patients.

In this study, the researcher will provide a review for the available strategies and provided services for management of CRC in the Gaza strip. Eventually the study results will cover over the strengths and weakness thus will benefit the health care system, will provide a corner stone with the useful information for minimizing the gap in management of CRC to enhance the quality of life for CRC survivors by preventing the disability and premature death resulting from it. Thus, help the policymakers and physicians to develop effective strategies and enhancing the provided services for CRC management and will guide its forward developing steps. Moreover, this study may provide tentative guidelines for other researchers to conduct field and give suggestions or highlights about improving the quality of cancer services.

#### 1.4 Aim of study

The aim of this study is to evaluate the current strategy for CRC management. This study may help us to identify the gaps in the strategy planning, to explore the implementation of this strategy, to provide recommendation to the policy makers for improving all aspects for the management of patients with colorectal cancer in order to improve overall and diseasefree survival and to improve health-related quality of life.

#### **1.5 Study objectives**

#### 1.5.1. General objective

To assess the available strategies and facilities for diagnosis and treatment of colorectal cancer in the Gaza Strip

#### **1.5.2. Specific objectives**

- 1. To ascertain the available strategies for the CRC diagnosis and treatment in the Gaza Strip
- 2. To investigate the available facilities and resources for managing CRC patients
- 3. To appraise CRC patients' perspectives about services they receive and its responsiveness to their needs
- 4. To detect the areas of strength and weakness of the management strategies and services provided for CRC patients

- 5. To define the main challenges, obstacles of the CRC management strategies and services
- 6. To provide suggestions for possible interventions to improve the program

#### **1.6 Study Context**

#### 1.6.1 Gaza Strip:

Gaza Strip is the residence of nearly two million people and internationally known as "The world's largest open-air prison". It is located in the southern of Palestine, a small country of about 27.009 km<sup>2</sup>, located in the east of Mediterranean Sea and the east of the Asia content. Syria and Lebanon bordered Palestine from the north, Jordan from the west, Egypt and Aqaba Gulf from the south. Gaza Strip is about 365 km<sup>2</sup>, with five governorates: North Gaza, Gaza, Mid Zone, Khan-Younis and Rafah (Annex 1).

According to Palestinian Central Bureau of Statistics (PCBS) (2018), the total number of populations in the state of Palestine was 4.78 million in the end of 2017, around 1.89 million in Gaza Strip and 2.8 million in the West Bank.

The average household in Gaza Strip is 5.6 persons and the population density is about 5324 individual/km<sup>2</sup>. The population of Gaza Strip is characterized by the dominance of age group below seventeen years old, which constitutes about 48% of the total population (PCSB, 2018). The life expectancy in Gaza Strip for males is 71.5 years and for female is 74.6 years (PCSB, 2016).

About the socioeconomic status, PCBS (2018) mentioned that the unemployment rate in Gaza Strip 48.2% and according to PCBS (2015), the gross domestic product per capita in GS is about 966.3 US\$. The World Bank (2017) estimates 80% of Gazans depend on many aid forms and despite this, the poverty rates is still high.

#### 1.6.2 Health and Health care system:

The cardiovascular disease is the first cause for mortality, as it is responsible for 57.1% of the total deaths followed by cancer, which is responsible on 6.9% of the total deaths (MOH, 2017<sup>a</sup>). The health care system in Palestine is a complex system, as there are multiple health providers with minimal coordination, no clear cooperation and no unified plan. The main health care provider in GS is the MOH along with the United Nations

Relief and Works Agency (UNRWA), Non-Governmental Organizations (NGOs) and finally the profit private sector.

According the national health strategy of MOH (2017-2022), there should be a comprehensive, unified health care system which aid in improving the provided health services and generally improving the health status of population (MOH, 2016).

Nearly 95.4% of the total Gaza Strip populations are covered by health insurance (PCSB, 2018). The total number of hospitals in Gaza Strip is thirty and the total number of hospital beds is 2999. MOH is responsible on thirteen hospitals with a total number of beds 2243 (MOH, 2017<sup>b</sup>). Three main hospitals are responsible on the cancer services in Gaza Strip, Al-Shifa hospital, El-Rantisi Specialized Hospital and the European Gaza Hospital. There are many facilities present for the diagnosis and treatment of CRC. In the other hand, the majority of facilities needed for the diagnosis and treatment for CRC are not present in our hospitals and in order to fill the gap the referral system to West Bank, East Jerusalem, Jordan, Egypt and Israel is found.

The cancer services generally in Gaza Strip characterized by instability, incomplete, shortage of most essential therapies, shortage of most needed cancer services, absence of training opportunities, poor referral system with long crowded lists. There are some areas of cancer surgery completely absent as palliative surgery and the surgery of some types of cancer (Abu Amer, 2012).

#### 1.6.3 Al-Shifa Hospital Complex:

Al-Shifa Hospital Complex is the main hospital for all the population living in the five governorates of Gaza Strip. It was established in the year of 1964 in the west part of Gaza city on 42 km<sup>2</sup>, which started as small camps and developed over the previous years (Al-Shifa Hospital records, 2013). Al-Shifa Hospital is in reality a medical Complex with 504 beds, composed of four hospitals: Medical Hospital, Surgical Hospital, Specialized Surgical Hospital, Obstetrics and Gynecology Hospital. The onco-hematology Department in Al-Shifa Hospital was established before twenty-five years as one room and over the last years, it provides diagnostic services for patients; which includes clinical, histopathological and radiological diagnostic services (MOH, 2017).

#### **1.6.4 European Gaza Hospital:**

The hospital began as a project granted by the European Union to the Palestinian people in 1987. Since there was no legitimate authority in this period, UNRWA was entrusted with the establishment of the hospital with European funding. The work started on the establishment of the hospital in 1993 and ended its funding in 1996. In July 1999, the international team started working in the hospital with a local Arab team. It was completed in October 2000 and the work of the local Arab team continued (European Gaza Hospital records, 2013). Currently the European Gaza Hospital is considered the second main hospital for cancer services in Gaza Strip with a total 247 beds (MOH, 2017<sup>b</sup>). The hospital provides diagnostic, treatment and follows up services. The hospital has a department for the cancer and hematology services and has outpatient clinic with total number of 29 nurses and 6 physicians (European Gaza Hospital records, 2013).

#### **1.6.5 El-Rantisi Specialized Hospital:**

El-Rantisi specialized Hospital constructed in 2006. The oncology pediatric department was constructed in El-Nasser Pediatric Hospital in 1998 and was transferred to El-Rantisi specialized Hospital in April 2008. Temporarely, oncology adult department was transferred from Al-Shifa Hospital to El-Rantisi Specialized Hospital in 2015. The oncology department consists of 30 beds, 15 for the males' cancer cases and the rest for the females' cancer cases. The oncology department has oncology inpatient clinic from Sunday to Thursday, with total of 30 practical nurses and 6 physicians divided on the outpatient clinic and the main department (El-Rantisi Specialized Hospital medical records, 2015)

#### **1.6.6 Palestinian cancer registry:**

Cancer registry can be defined as a system for information collection about cancer patients, storage, analysis and interpretation of data through a computerized system (Centers for Disease Control and Prevention, 2015). The Palestinian cancer registry was established by the cooperation between MOH and the Middle East cancer consortium that is considered a population based registry in 1996, and started its regular work in 1998. The main purpose for the existence of PCR is to define the burden of the cancer problem and the pattern of its occurrence. The cancer registry in Gaza governorates extends from 1995 until present with the registry including all cases from its different sources. The cancer registry collects data from five main sources; which includes; governmental hospital,

governmental and private histopathological centers, variable radiological centers, treatment abroad referral records and the death certificates (MOH, 2015).

#### **1.7 Definition of items**

**Evaluation:** Systematic collection of information, activities, characteristics, program outcomes to make judgment about merit of a program to improve effectiveness, inform decisions about future programming (Patton, 1997).

**Colorectal cancer management:** CRC management is a multidisciplinary method, guided by staging and histopathology. It includes diagnosis, screening, staging, adjuvant therapy, surgery, management of advanced cancer and follow-up (Leslie & Steele, 2002).

**Screening:** The presumptive identification of unrecognized disease or defect by the application of tests, examinations, or other procedures, which can be applied rapidly (Commission of Chronic Illness, 1957).

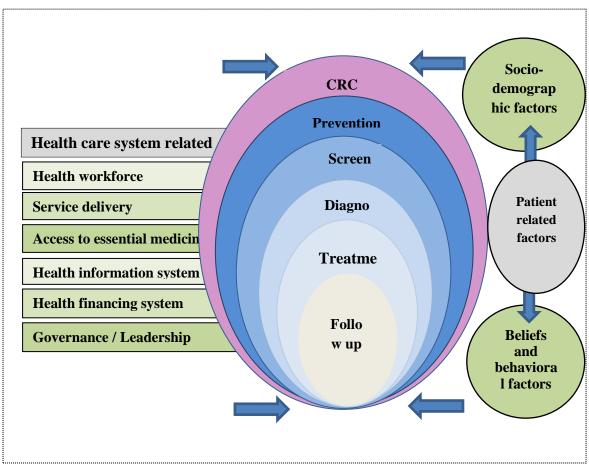
**Health system:** A health system consists of all the organizations, institutions, resources and people whose primary purpose is to improve health (WHO, 2000<sup>a</sup>)

**WHO building blocks:** WHO framework that describes health systems in terms of six core components or "building blocks": (i) service delivery, (ii) health workforce, (iii) health information systems, (iv) access to essential medicines, (v) financing, and (vi) leadership/governance. The six building blocks contribute to the strengthening of health systems in different ways (WHO, 2010<sup>a</sup>)

# Chapter Two Literature Review

### 2.1 Conceptual framework

The conceptual framework has been constructed after reviewing the related literature for CRC management and the most feasible and accepted variables have been selected; some other variables are not mentioned because of some limitation and restrictions. The purpose for constructing such framework is to provide logical pathway through which the phenomena of concern to be studied. The following figure (2.1) demonstrates the major dimensions, which are dominantly affecting the CRC management quality.



#### Conceptual framework of the study

Figure 2.1: Conceptual Framework of the study

The main independent factor (WHO building blocks) and (patient related factors) predominantly affects the dependent factor (CRC Management). The independent factors are mainly concerned of items such as health workforce, infrastructure for service delivery,

access to essential medicine, health information system, and governance/leadership; they are known internationally and recommended by WHO as key indicators and effective measures for the health care system capacity. The WHO blocks have benefits as it considered a tool for monitoring and evaluation; they reduce the transaction costs, increase the efficiency and decrease the financial burden on the countries. The six WHO building block scan be classified as three groups: crosscutting; the leadership/governance and the health information system, where they considered the basis of the health care system. The key inputs of the health care system include financing and health workforce, the third group, namely the health care system outputs include: medical products and the service delivery (WHO, 2010<sup>a</sup>).

The health care system is considered to provide good health services when it was able to provide effective, save, quality services to those who need them, when and where they need them with a minimum waste of the resources. A well performing health workforce is one which works in effective, efficient way to achieve the best health outcome in the given available resources and circumstances, and there should be a sufficient number of health staff, distributed fairly. The health information system is considered well function when the production, analysis and dissemination with reliable and timely use of the health information. A well-functioning health care system provide equitable access to the essential medical products, vaccines and technologies of good quality, safety, efficiency, cost effectiveness. A good health financing raises adequate fund to ensure people can use needed services and to be protected from financial catastrophes and impoverishment. Leadership and governance is the most complicated dimension, but it is considered the most critical component of the all blocks. The governance required both technical and political issues in order to reconcile the growing demand of the health services (WHO, 2010<sup>a</sup>). The second component of the framework is the process, which represent the link between the inputs and the output. The process is the steps that done by the health workforce under the umbrella of the infrastructure for service delivery, access to essential medicine, health information system, and governance/leadership to reach to the optimal care for the CRC patients. The process starts with prevention, screening, diagnosis, treatment, palliative care, referral system between variable health care providers.

The last category for the framework is the outcome, which is the patient satisfaction of the provided care, which indirectly can reflect the quality for the provided care. The patient centered outcome (PCO) helps both patients and the health providers to communicate and

to create informed health decision to improve the health care system and enhance the health care options (PCOI, 2013).

The other independent factor affecting the CRC management is patient related factors as the socio-demographic and tumor related factors.

#### 2.2 Literature review

#### 2.2.1 Overview about cancer:

Cancer problem is the main cause for mortality in all countries regardless the income status. The number of cancer cases is expected to increase and grow rapidly, since the population grows more, increased elderly population across the world and the risky life style behaviors, which adopt the increasing number of cancer patients (Toree et al., 2016).

The Cancer myth "the disease of affluence", as it is mostly affect the people of rich countries because of their lifestyle habits, but the world info graphics does not support this myth as in United States the lung cancer is twenty-six times more than Tanzania, but Tanzania rate of cervical cancer is nine times more than United States. The geographic pattern of cancer depends on the behavioral, lifestyle pattern and the power of the preventive measures (Elert, 2012).

The causes and types of cancer vary across the world and the burden of cancer is massive that doesn't affect only individuals, it affect all the community and put challenges in front of the whole health care system for both the rich and poor countries (WHO, 2003). As treating a single cancer patient needs communication and coordination of several health care system inputs which require thousand millions of dollars in high-income countries (Horton and Gauvreau, 2015), so this will aggravate the current CRC management status.

#### 2.2.2 Colorectal cancer

CRC begins as a growth called polyp in the inner lining of rectum and colon; the ability of the polyp depends on its type, where the adenomatous polyp has the highest probability to turn to cancer where it is known as precancerous lesion. The adenocarcinoma is the most common type of CRC, constitutes about 95% of all types of CRC and some types of adenocarcinoma have the worst prognosis as signet cell and mucinous adenocarcinoma (American Cancer Society (ACS), 2017).

Smith et al. (2006) found that CRC has primary and systemic symptoms, as for the primary symptoms in early cancer 89% of the patients presented by rectal bleeding, 58% by change bowel habits and 24% had abdominal pain, which in comparison to the advanced group in which the change in bowel habits and abdominal pain are more prominent. About the systemic symptoms in both the early and the late cancer decreased appetite, weight loss and generalized tiredness.

The colorectal cancer in Gaza Strip has a special condition, where the diagnosis is often late as there is no national CRC screening program, which aggravate the problem of late diagnosis and not curing treatment, as concluded by Qumseya et al. (2014) that there are many cultural and religious barriers to CRC screening program in Palestine.

Because early diagnosis and detection of CRC directly related with the outcomes, it is important to understand all information related to CRC from it is screening toward it is treatment (Colorectal Surgery Institute, 2018).

#### 2.2.3 Colorectal cancer epidemiology

#### - International colorectal cancer epidemiology:

According to World Cancer Research Fund International (2012), CRC globally is the third most common cancer among males and the second most cancer among females with 55% of cases in the developed countries. Arnold et al. (2016) found that based on the incidence and mortality rates over the past ten years, the world could be divided to three categories: increasing or stable incidence and mortality, increasing incidence and decreasing mortality and those with decreasing incidence and mortality rates. The group of increasing or stable incidence and mortality rates. The group of increasing or stable incidence and mortality rates. The group of increasing or stable incidence and mortality comprising several Eastern European countries, Latin America and Asia, the second group, is the group of increasing incidence and Singapore. The last group is the group of decreasing both incidence and mortality rates including the highest human index, which restricted to Australia, Iceland, New Zealand and Japan.

#### - Regional colorectal cancer epidemiology:

The Arab world is the world of nearly 350 million people which expanded from Syria and Lebanon in the north, through to Morocco in the west, to Yemen in the West and to Iraq in the east.

According to Salim et al. (2009), the incidence of CRC is considered to be low, where in some countries is considered the second most common cancer after the breast cancer in both sexes. Abou-Zeid et al., (2002) find that in Egypt 38% of the patients are younger than 40 years and 75% of the lesions are left sided. According to Shpitz et al. (2006) in comparison with the other Arabian countries the CR cancer patients in Palestine tend to be younger and have more aggressive cancer as there is high percentage of undifferentiated and mucinous cancer with advanced stages. Arafa & Farhat (2015) show that the incidence of CRC is much lower than developed countries, but the incidence in Arabian countries is increasing over the past ten years. Moreover, this can be resulted from the dramatic change in the lifestyle and food consumption in the previous years, as the traditional food is replaced with the fast western food, this is augmented by sedentary life and decreasing activities.

#### - Local colorectal cancer epidemiology:

According to recent MOH report, the CRC is the second common type in Gaza Strip with 420 registered cases and constitutes about 12.5% of all cancer cases and it is considered the first cancer type among males, which constitute about 15.5% of all male cancers with incidence of 11.1/100.000 population (MOH, 2018).

The CRC is increased rapidly through the last ten years, as through year 2009 to 2014, it was 10% of all cancer types with 230 registered cases and among males, it was the second cancer after lung cancer.

#### 2.2.4 Colorectal cancer survival

The world has a remarkable progress in CRC screening, diagnosis, treatment protocols and improvement in interventions result in improvement in the CRC survival rate (Hassan et al., 2016). Many factors can affect the CRC survival as the stage of diagnosis and the timing of detection (American Cancer Society (ACS), 2011). The survival rate is defined as: "The percentage of people in a study or treatment group who are still alive for a certain period of time after they were diagnosed with or started treatment for a disease, such as cancer" (National Cancer Institute, 2016).

It was found that the survival rate of CRC disease in Gaza is affected by co-morbidity status, smoking, stage of diagnosis, tumor grade, tumor site, and treatment type (Alrun, 2017).

#### 2.2.5 Risk factors for CRC

#### - Family history:

The CRC occurs in three patterns: sporadic or familial. Sporadic cases exists in 70-75% and familial in 20-25%. The patient is considered with positive family history if he has first-degree member with CRC or colon polyp before age of 60 years, or if two or more first-degree relatives diagnosed with CRC at any age (Amersi et al., 2005). For 7493 first-degree relatives of 523 case-control pairs, the odd ratio (OR) was 1.8 (95% Confidence Interval (CI), 1.2 to 2.7) for one and 5.7 (CI, 1.7 to 19.3) for two affected relatives. The risk increased for patients have parents and siblings diagnosed with CRC with 2.1 times greater than control patients (CI, 1.4 to 3.1), 3.7 times increased risk with diagnosed CRC before age of 45 (CI, 1.5 to 9.1).

Based on 8091 cases of CRC in 16 studies, the average risk for CRC is higher among individuals with family history for CRC compared with those with no family history (RR = 1.80, 95% CI: 1.61-2.02). The relative risk among the studies evaluating male-female mixed population (1.90, 95% CI: 1.67-2.17) where higher than the relative risk among the studies evaluating only female population (1.60, 95% CI: 1.33-1.92) (Johnson et al., 2013).

#### - Body Mass Index (BMI):

Twenty-three studies were systemically reviewed with (168,201) participants, they found that subjects with a BMI  $\geq$  25 had a significantly higher prevalence of colorectal cancer (OR=1.24 (95% CI: 1.16–1.33), P<0.01) when compared to those with BMI<25. There is a positive association between higher BMI categories and the prevalence of CRC (BMI: 25–30 vs. BMI<25; OR=1.21 (95% CI: 1.07–1.38), P<0.01; BMI $\geq$ 30 vs. BMI<25; OR=1.21 (95% CI: 1.07–1.38), P<0.01; BMI $\geq$ 30 vs. BMI<25; OR=1.32 (95% CI: 1.18–1.48), P<0.01) and revealed a dose–response relationship (Okabayashi et al., 2012).

In Ewha Mokdong Hospital, Seoul, Korea, between February and June 2005, 1744 asymptomatic patients (946 men, 798 women) underwent colonoscopy for cancer screening. Positive association found between BMI and the prevalence of colonic adenoma and the advanced polyps in relatively young patients in both genders (men in their thirties, P < 0.05; women in their forties, P < 0.05) (Kim et al., 2007).

#### - Physical activity (PA):

The physical activity is protective against the CRC; PA reduces the risk for CRC by 20-25% among both females and males in dose response relationship (Namasivayam & Lim, 2017).

Cohort study was performed for 74870 female participants, (50-79) year's age group; they were followed over 13 years where the physical activity and sitting hours (ST) where reported during the study period. Over a 13 year follow-up period, 1145 incident cases were documented, compared with inactive women ( $\leq$ 1.7 MET-h/week), the relative risk of CRC in the high PA (>20 MET-h/week) group was 0.81 (95% confidence interval: 0.66-1.00; P for trend 0.04). Compared with inactive women with high sitting hours ( $\geq$ 10 h/day), there was a trend toward reduced CRC risks with higher PA irrespective of ST level (interaction=0.64). As conclusion, there is an inverse relationship between the PA and the risk for CRC incidence (Gorcyzyca, 2017).

#### - Tobacco smoking:

In the period of 1999-2003, 702 CRC cases diagnosed and 717 controls were frequencymatched by 5-year age group and sex with controls. The study found independent association between cigarette smoking and CRC, there was a 49%, 36% and 96% higher risk of CRC among all, former and current smokers, respectively, compared to nonsmokers. The adjusted OR showed that the risk of CRC increased significantly with smoking cigarette years, the number of cigarettes smoked daily, and cigarette pack years. The risk of CRC decreased significantly with years of abstention from smoking (Zhao J. et al., 2010). Whereas 68,160 Norwegian women, aged 30-69 years, followed from year 1996 to 2005, 425 incident CRC cases. Ever smokers had a 20% increased risk of CRC (RR = 1.2; 95% CI = 1.0-1.5) compared to never smoking (Gram, 2009).

#### 2.2.6. Colorectal cancer management strategy

The World Health Assembly committed that all countries should develop and apply a national cancer control programs (WHO, 2005). This has a goal to reduce the morbidity and mortality ratios of cancer disease in general and improve the quality of life of the patients. A broad national cancer program evaluates the variable ways to control disease and applies those that are the most cost-effective and beneficial for the largest part of the population. The national cancer control program should contain primary prevention, early

detection, diagnosis, treatment, palliative care, cancer registration and cancer research. Such programs should be reviewed and disseminated between all the stakeholders, supported by the national MOH, respected and to be implemented (WHO, 2002<sup>a</sup>).

In 2001, a survey of 167 WHO nations assess the national capacity for prevention and control of (non-communicable diseases) NCD including the cancer disease, as a result, they approximately found 83 only of 167 countries had a cancer control plan or policy. About two-thirds of the countries indicated the availability of national guidelines for prevention, and almost half specified that cancer management guidelines had been produced and two-thirds of the countries did not provide supporting documents confirming the existence of these plans and guidelines (Alwan, 2001).

People involved in framing and applying the national strategy for cancer control program should be health professionals, cancer experts, health service workers, patients' groups and representatives from the sector involved. In addition, governmental, non-governmental and private health providers should work together closely to develop a successful cancer control program (WHO, 2002<sup>a</sup>).

#### 2.2.6.1 Prevention of CRC:

Cancer prevention is known to eliminate or minimize the exposure to known environmental causes of cancer. It is estimated that 50% of the world cancers attributed to world cancer are attributed to three factors: tobacco, infection and unhealthy lifestyle (diet, obesity and lack of physical activity) (WHO, 2009).

Many factors enhance the occurrence of CRC and it is difficult to find the exact factors that should be prevented to decrease the incidence of CRC.

#### - Diet:

Reducing red meat to less than 70 g/week, will result in decreasing CRC incidence hypothetically by 7-24% (Norat, 2002). Whereas the total fiber intake found to have an inverse relationship with the incidence of CRC, as OR were for the components of the fiber as follow: 0.57 for total fibers, 0.55 for soluble non-cellulose polysaccharides, 0.58 for total insoluble fibers, 0.57 for cellulose, 0.62 for insoluble non-cellulose polysaccharides and 0.62 for lignin. When fiber was classified according to its source, the OR was 0.60 for vegetables, 0.78 for fruit and 0.74 for grain fiber (Levi, 2001).

#### 2.2.6.2 CRC screening:

CRC meet the requirements for screening according to Wilson and Jungner criteria as the "gold standard of screening assessment" (Wilson et al., 1968). The criteria that CRC achieves include its high incidence rate, its long pre-symptomatic phase, its recognizable originator and the correlation between the tumor stage and mortality rate.

Screening for CRC appears to be cost-effective compared to no screening (Pignone et al., 2002). However, CRC screening programs must be modified to the risk of each population. An average-risk population is defined as a population of individuals aged 50 years or older, with no additional risk factors. The recommended screening for the average-risk population is one of the following: an annual or biennial fecal immunochemical test; sigmoidoscopy every 5 years; or colonoscopy every 10 years (Navarro et al., 2017).

The perfect colorectal cancer screening modality should be cost-effective, increase the extended life-years, and permit long intervals between tests with high patient agreement and low risk to the patient. Although no single colorectal cancer screening technique is perfect, many options exist as fecal and serum tests which consists of fecal occult blood test, fecal immunological based stool test, DNA stool analysis, serum markers (carcinoma embryonic antigen (CEA) and carbohydrate antigen (CA 19-9)), where CEA and CA 19-9 are considered not useful for detection of CRC. Other tests used for CRC screening are the imaging tests as barium enema and computed tomography (CT), the last option for screening are the optical tests as flexible sigmoidoscopy (FS) and flexible colonoscopy (FC) and both are used for detection of CRC and as a therapeutic option in the same time (Geiger & Ricciardi, 2009).

The U.S. Preventive Services Task Force (2008) recommended both FS and FC as screening modalities for CRC detection, but concluded the need for quality initiatives for colonoscopy along with all operator-dependent screening tools.

#### - Delay in screening of CRC:

Adults evaluated between 2011 and 2014 with a diagnosis of colorectal cancer were identified. Clinical notes, endoscopy reports, surgical reports, radiology reports, and pathology reports were reviewed. The study population was 54% males with a mean age of 58.9 years. Initial diagnosis was established at the time of colonoscopy screening in 10.7%, diagnostic colonoscopy in 79.2%, and during emergent surgery in 7.1%. Cancers

diagnosed at the time of screening colonoscopy were more likely to be stage one than cancers diagnosed at the time of diagnostic colonoscopy or emergent surgery (38.5%, 7.2%, and 0%, respectively). Median tumor size was 3.0 cm for the screening colonoscopy group, 4.6 cm for the diagnostic colonoscopy group, and 5.0 cm for the emergent surgery group. At least 31% of patients diagnosed at the time of screening colonoscopy, 19% of patients diagnosed at the time of diagnostic colonoscopy, and 26% of patients diagnosed at the time of emergent surgery had never undergone a screening colonoscopy (Moreno et al., 2016).

#### 2.2.6.3 Diagnosis of CRC

The diagnosis of CRC is done by both laboratory and imaging modalities.

#### 2.2.6.3.1 Laboratory modalities

#### - Complete blood count:

A retrospective case-control study of all cases of colon cancer diagnosed over a 5-year period was performed to determine the frequency of blood count abnormalities in these patients upon presentation. One hundred twenty-seven patients had right-sided colon cancer: 84% of them had an elevated red cell distribution width. Ninety-eight patients had left-sided colon cancer: 50% had an elevated red cell distribution width. The red cell distribution width was 84% sensitive and 88% specific for right-sided colon cancer. An elevated red cell distribution width may help better identify those patients who should be referred for full colonoscopy (Spell et al., 2004).

#### - Carcino-embryonic antigen and carbohydrate antigen 19-9:

Zhang, Lin & Zhang (2015) shows that the levels of CEA and CA 19-9 increasing significantly in the patients of CRC than the patients of benign colon diseases, the study suggested that both CEA and CA 19-9 should be conducted simultaneously for the diagnosis of CRC in order to obtain reliable detection of CRC. Although the tumor markers of CEA, CA 19-9 are widely used currently in diagnosing, staging and screening for CRC, they have low diagnostic sensitivity and positive rates.

#### - Fecal occult blood test (FOBt):

Non-invasive laboratory test, simple to detect the presence of occult blood in the stool, its sensitivity ranges from 37.1% to 79.4% depend on the brand and the type of the test, its

value for detection and screening of CRC. The disadvantage for the fecal occult blood is the need for repeating the test in regular intervals (Levin, 2008).

#### 2.2.6.3.2 Imaging modalities

The aim of the diagnostic modality is to achieve adequate examination of the entire colon and rectum. Effective diagnostic interventions in symptomatic patients suspected of having colorectal cancer need to have very high sensitivity, for the detection of cancers and acceptable sensitivity for detection of adenomas with significant potential for malignant transformation. Where sensitivity is defined as "a diagnostic intervention with very high sensitivity will detect the vast majority of patients with colorectal cancer and very few patients with the disease will be missed". They must also have high specificity, be as safe as possible and be acceptable to patients, as all these investigations are unpleasant and invasive. Where specify is defined as "a diagnostic intervention with very high specificity will identify only those patients who truly have colorectal cancer and it will not falsely identify as positive, those patients who do not have the disease" (National Collaborating Centre for Cancer (United Kingdom), 2011).

#### - Endoscopy:

The first complete examination of the colon is a flexible fiber optic endoscope that is reported by Wolff and Shinya in 1971. Recently, the colonoscopy is considered the gold standard for colonic mucosa examination. The diagnosis CRC can be confirmed after biopsy in a known malignant pathology. The colonoscopy removes all detected polyps, independent on the histology type- adenomatous or hyperplastic. Not all of them must undergo removal. The polyps vary in size and polyps that less than 5 mm cannot be detected by endoscopic. For detection of polyps smaller than 5 mm, the virtual colonoscopy is the alternative to the conventional colonoscopy (Ignatov, 2014).

There are many appropriateness criteria for improving colonoscopy indications, which are needed as the resources are limited and adherence to the appropriate indications for colonoscopy is necessary. The appropriateness guidelines may be useful not only to prevent unnecessary colonoscopies and potential risks resulting from them, but also to prioritize colonoscopy. The criteria are American Society for Gastrointestinal Endoscopy, European panel appropriateness of gastrointestinal endoscopy I criteria and EPAGE II criteria (Gimeno-García and Quintero, 2015).

#### The criteria for appropriateness of colonoscopy

# American Society for Gastrointestinal Endoscopy, European panel appropriateness of gastrointestinal endoscopy I criteria

The first guideline for the American Society for Gastrointestinal Endoscopy (ASGE), which was consist of 27 general indications for colonoscopy (ASGE, 2000). The application of the modified ASGE slightly increases the rate of appropriateness of colonoscopy and increase the rate of CRC detection, which was presented by a prospective study, including 495 consecutive outpatients were referred for colonoscopy before the educational course about the appropriateness for colonoscopy and 522 after its completion. The post-course group rate of inappropriateness was significantly lower than the precourse group (Grassini, 2008).

#### **EPAGE II criteria**

EPAGE I and ASGE appropriateness guidelines are not widely used, as significant lesions are detected in about 30% of inappropriate colonoscopies according to EPAGE I and ASGE criteria (Bersaniet al, 2004). Recently, an updated version of the EPAGE-I criteria for colonoscopy have been published (EPAGE-II criteria). The main indications for colonoscopy according to EPAGE-II criteria: iron deficiency anemia, hematochezia, discomfort in the lower abdominal pain persisting for more than 3 months, uncomplicated chronic diarrhea, assessment of ulcerative colitis, assessment of crohn's disease, CRC screening, surveillance of colorectal cancer after polypectomy, surveillance of colorectal cancer after polypectomy.

#### - Virtual colonoscopy:

Virtual Colonoscopy uses computed tomography (CT) imaging virtual- reality technology for screening the entire colon, which is reconstructed from abdominal CT images. The virtual colonoscopy has a higher sensitivity and specificity rates compared to conventional colonoscopy for the detection of polyps, which are 8 mm and larger by the same bowel preparation, and for polyps larger than 10 mm they have a comparable performance (Ignatov, 2014).

#### -Endorectal ultrasound:

Endorectal ultrasound (ERUS), remain the most attractive, widely used and effective modality as it is considered as an extension for the physical examination. The accuracy for

endorectal US ranges from 80-95% for T-staging and 70-75% for N-staging, the levels are higher than that of Magnetic Resonance Imaging (MRI), which is respective 75 to 85% and 60 to 70% observed for MRI (Ptok, 2006).

ERUS can accurately measure the size, circumference, and distance of the tumor from various anatomic landmarks (e.g., anal verge, anorectal line), which can help to decide the mode of therapy (Edelman & Weiser, 2008).

#### - Magnetic Resonance Imaging (MRI):

MRI is the recommended modality for initial staging, due to its high accuracy for the definition of localization, determining the total extension and the relationship of the tumor to the peritoneal reflection. Adding to this, MRI is accurate in measuring the distance between the anorectal junction and the distal part of the tumor. It is also accurate for determining the length of the tumor (Ignatov, 2014)

#### - Computed Tomography (CT):

CT is the initial modality for diagnosing a patient who has gastrointestinal symptoms. The Radiologists can effectively discover CRC with a high degree of accuracy. Minimizing the oral contrast were helpful in improving the detection rate of CRC (Mangat et al., 2018).

#### 2.2.6.3.3 Factors affecting delay in CRC diagnosis

#### - Factors related to the patient:

Several factors can lead to CRC diagnosis delay related to the patient; Andersen's Model of Total Patient Delay can summarize the main causes for patient delay in seeking medical help and this will result in delaying the diagnosis of CRC. A theoretical framework, defines five time intervals in the decision-making process: Appraisal delay (time between the detection of symptoms and inferring illness); illness delay (period when the patient contemplates between consulting a medical practitioner or self-treating the illness); behavioral delay (delay in making an appointment with the general practitioner (GP)) (Anderson & Cacioppo, 1995).

Appraisal delay can be found in the cross-sectional, mixed methods design collected data we done through interviews and medical record reviews for 252 CRC patients. The main reasons are found for delay in the CRC diagnosis; fear of receiving diagnostic tests in 24.3% (p < 0.01), feeling too embarrassed to seek care in 11.9% (p = 0.01), patient belief

that she/he was too young to have cancer in 11.6% (p = 0.05), and belief that the symptoms experienced were not serious in 39.7% (p < 0.01). Patients who reported a financial barrier to accessing health care (p < 0.01) were more significant for CRC diagnosis delay when compared with the proceeding factors (Siminoff et al., 2014).

#### - Factors related to the practitioner delay:

One of the most complex factors lead to delay in CRC diagnosis which is the physicians, more the general practitioners; the first contact with the patients. Several factors can lead to late diagnosis of CRC despite seeking medical help early.

Mitchell et al. (2008) did a systematic review for twenty-nine papers that considered factors that influenced practitioner delay. He described two main factors for practitioner related CRC diagnosis delay, which are responsible on 75% of the delay. The first was initial misdiagnosis, through either prescribing symptomatic treatment or attributing symptoms to other benign conditions. In fact, missed opportunities to diagnose CRC before endoscopic referral occur in 31%-34% of patients presenting with symptoms, entailing an average delay from the first visit > 200 day. The main diagnostic key was iron- deficiency anemia, which was associated with the longer delay to referral (> 300 day). The second main factor was failure to examine or investigate. Studies showed a frequent lack of physical examination among patients with lower abdominal symptoms, especially digital rectal examination.

A cross-sectional study was done of all incident cases of symptomatic CRC during 2006-2009 (795 incident cases) in five Spanish regions. Data were obtained from patients' interviews and reviews of primary care and hospital clinical records. Symptoms to diagnosis interval for CRC were 128 days. Women experienced longer intervals than men did. Symptom presentation such as vomiting or abdominal pain and the presence of obstruction led to shorter diagnostic or treatment intervals. Time elapsed was also shorter in those patients that perceived their first symptom/s as serious, disclosed it to their acquaintances, contacted emergencies services or had trust in their GPs. Primary care and hospital doctor examinations and investigations appeared to be related to time elapsed to diagnosis or treatment (Estevaet al., 2013).

Between year 1995 and year 2008, 62 patients had been identified with CRC diagnostic delay, the mean delay for diagnosis of CRC was six months, this delay was with a

negatively impact on treatment in 20% of patients and the prognosis in 15% of the patients. There were 23 patients have metastasis at time of diagnosis, as the delay was caused by incomplete consideration of the symptoms hematoschisis or anemia, changed bowel routine, or incomplete clinical or radiological examination and by misinterpretations of the results. No impact of duration of delay on survival was identified. The importance of identifying concomitant metastatic disease at diagnosis was overwhelming (Hafstrom et al., 2012).

A survey was done on 93 newly diagnosed CRC patients with histopathological proven adenocarcinoma. Twenty-two (26%) patients delayed seeking treatment because they thought their symptoms were not serious and 12 (14%) believed that their family physicians had taken inappropriate action. Fifteen (18%) patients attributed their delays to waiting too long for specialist referral and diagnostic tests (Tomlinson et al., 2012).

#### - Factors related to the hospital delay:

The main indicator for colonoscopies is the evaluation. Hematochezia was the most frequent indication (31.5%) followed by colorectal cancer-related indications (27.3%). The clinical diagnosis was only established in 41%. The inappropriate use of colonoscopies when compared with EPAGE criteria (27%) than when compared with EPAGE II criteria (17.4%). Inappropriate use was less with older age, in hospitalized patients, with referrals from internal medicine, and in colonoscopies with clinically relevant diagnoses (Argüello et al., 2012). This study when compared with the European Panel for the appropriateness of use of the colonoscopies; EPAGE and EPAGE II criteria were applicable in 95.3% and 98.0% referrals, respectively. A total of 166 (57.8%) patients were considered appropriate by EPAGE II (Eskeland et al., 2014).

There is a growing demand for colonoscopy requests related to the screening of patients, so there is a need for prioritization criteria in order to reduce delay in patients with a high suspicion of CRC, preventing them from being affected by waiting lists (Vega et al., 2015).

#### 2.2.6.4 Treatment of CRC

#### - Stage I to III

The primary treatment of CRC stage I to III is primary surgical resection of the primary tumor and the regional lymph nodes. Resection of adequate number of regional lymph nodes is essential, because the number of involved lymph nodes significantly correlates with 5-year overall survival. Adjuvant chemotherapy is needed after surgical resection for stages II and III to decrease the risk of recurrence and local metastasis (Kim, 2010).

### -Stage IV

Chemotherapy for advanced or metastatic disease includes the use of multiple drugs as single agents or combination agents. Differencing disease metastasis at one organ site from metastasis at more than one organ site is important. Optimal use of all therapeutic agents improves the survival in patients with metastatic disease (Matin et al., 2018).

#### - Psychosocial support

The cancer has turned into a life-threatening chronic condition because of increasing early detection, increasing incidence of colorectal cancer cases and advances in treatment in the past decades, this will increase the life expectancy of such patients, and this means increasing number of people will need medical treatment for cancer, long-term surveillance, and palliative care in the future. From here, the importance of psychosocial care of cancer patients emerges (Weis, 2015).

The treatment of cancer has a great psychological and psychosocial impact on the patients and their families, where it is accompanied by a cascade of substantial changes that encompass the physical, emotional, spiritual, interpersonal, and social dimensions of the person with cancer. As a high percentage of cancer patients suffer from emotional symptoms and psychological conditions then it is extremely important for cancer care professionals to provide integrated and comprehensive care in oncology departments (Grassi et al., 2017).

#### - Palliative care

The palliative care is "An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". As the incidence and mortality of cancer will increase in the next 20 years, access to palliative care will be the core essential need in the colorectal cancer management care (WHO, 2002<sup>a</sup>)

The Palliative care is an active, complete care and treatment for cancer patients with incurable diseases and short expected time left to live (Faber-Langendoen & Lanken, 2000).

The palliative care is rarely accessible in Lower Middle Income Countries (LMICs) (Krakauer et al., 2017). Inequality of access to palliative care is one of the largest disparities in worldwide health care (Gwyther & Krakauer, 2011).

The WHO recommends an approach to integrate the palliative care into health care services in general, and into the primary care in particular, in a cost-effective manner and to reach all those who need the palliative care (WHA67, 2014).

According to Abu Hamad et al. (2016) reflects the availability of palliative care, is 68.72%, which means that the provided palliative care services are reasonably moderate. The medical aspect of care provided by physicians elicited the highest score (74%); meanwhile, the nursing aspect of care scored less (68%). Younger patients, whose malignancies were discovered at early stages and those who were treated in one single hospital, elicited higher scores with statistically significant differences in comparison to their counter groups. Despite being available, palliative care services are not well-framed in Gaza's hospitals.

#### **2.2.6.4.1 Factors lead to delay treatment**

# - Sociodemographic characteristics of the patient and clinic-pathological characteristics

Several sociodemographic factors are found significantly affecting the time of onset of the first treatment, male sex, low level of education or no formal education, BMI (28±5.1), exsmoker and asymptomatic at diagnosis are responsible on the delay of the onset of treatment. Regarding the clinic-o-pathological characteristics, the most relevant tumor characteristics were small local extension, the absence of nodes metastasis and perineural invasion. Treatment delays in patients with tumors presenting normal values for carcinoembryonic antigen and for cancer antigen 19-9 were greater than among patients presenting abnormal values for these parameters (Zarcos-Pedrinaci et al., 2017).

About the demographic characteristics, older age and American Society of Anesthesiologists were factors for not receiving the adjuvant chemotherapy early, as overall survival was 87.2% with the adjuvant chemotherapy and 58.5% with no adjuvant

chemotherapy (AC) in stage II disease, and 79.5% (AC +) and 24.6% (no AC) in stage III disease, respectively (Kim Y. & Kim W., 2015).

## - Financial characteristics

The financial status can significantly affect the timing of onset of the treatment. The insurance status of the patient had a significant influence on the onset of the treatment. Patients with additional private insurance had the shortest delay in treatment. In contrast, patients without insurance had the longest treatment delays. When exploring the social conditions of this subpopulation, we found that these patients consisted mostly of single house-wives with adult children, who had no income (Langenbach, 2003).

### 2.2.7 Evaluation

In 1998 the WHO define the evaluation as a systematic examination and assessment of the features of an initiative and of its effects, in order to produce information that can be used by those who have an interest in its improvement or effectiveness (WHO, 1998).

# **2.2.8** Effect of the WHO building blocks of the health system on the disease control programs

Mounier-Jack et al. (2014) found that the WHO building blocks worthy because it create a unified language, common vision and understanding as having one common international framework is more useful than having multiple frameworks and having such framework help to compare between national studies.

## A. Health workforce

Health workforce shortage has an impact on access of care in the societies. Having an adequate health workforce with a number proportionate to the number of population is necessary to provide the usual source of care. Health care professionals' shortage can limit the access to care by limiting the available services as in September 2018, 57.27% of primary health care specialist deficient areas located in rural areas (Rural Health Information Hub, 2017).

Truth (2013) recognized that no health without a workforce, and found that many countries suffered from shortage of some categories of health workers, the problem is augmented by ageing workforce as replacement is considered a challenge to most countries.

To create a functioning primary health care system, although it is important for diagnostic facilities and medication to be available, the most critical resource is the health workforce. In Thailand, there were strategies for rapid expansion of primary health care workforces and increase distribution to rural areas (Tangcharoensathein V. et al., 2013). Improving the health workforce availability, accessibility, acceptability and quality dimensions needs health workers to be motivated in an enabling environment, performance and quality of care assessment should be afforded a priority, estimation of future human resources for health needs and human resources information systems and data require strengthening and investment (Truth, 2013).

#### **B.** Affordability to essential medicine

Major cause for morbidity and mortality in low-income countries, can be treated and prevented by essential medicines. In many low-income countries, the needed essential medicines are not available, not accessible or not affordable (Escalante, n.d.)

Lack of access the essential medicines remain one of the main worldwide health problems, as when combining both governmental and private sectors, it is estimated that two thirds of the world populations have a good access to medications. It is estimated that by improving access to existing essential medicines, about 10 million lives per year could be saved. The major access obstacles could be summarized as: medicine financing, treatment costs and global trade agreements that could affect the access to essential medicines in low to medium income countries (WHO, 2004).

The WHO (2004) presents the equitable access to essential medicines framework through four dimensions. Rational selection refers to rationalize therapeutic choices. Improved use of medicines by consumers is also element of this dimension of access. Affordable prices take part in supply-side aspect of affordability. Sustainable financing enlists resource mobilization and pooling as well as reduction of patient out-of-pocket and catastrophic expenditures. Reliable health and supply system is defined as the aspects of health system strengthening that are not covered by the other three dimensions: procurement and supply of medicines, regulation and human resources. Quality assurance and management systems are assumed to underpin all access components.

#### C. Service delivery

### - Diagnostic facilities

The insufficient number of diagnostic facilities was magnified by other health systemrelated barriers such as lack of funds for further diagnostic tests, shortage of specialists at referral facilities, deficiencies of the laboratory services, which could be unreliable and poorly equipped, limited access to telecommunications and lack of institutional support and opportunities for training (Huaynate et al., 2015).

### - Building design

Health care providers, architects, and hospital directors believe that the hospital building design and environment can benefit the satisfaction of health care providers as well as patient satisfaction and outcomes. Designing of hospital building for safety and quality can improve patient outcomes and safety, promote healing, increase patient satisfaction, and reduce costs and this can improve the quality of care and patient outcomes (Reiling et al., 2008).

### **D.** Health information system (HIS)

Health information system helps to access to patient information easily, improving documentation of medical files, decrease error and missing data. Using such system facing many barriers, the barriers could be divided to human and non-human factors. The human factors include the negative attitude of the society toward using HIS and the absence of incentive to use system (Ahmadian et al., 2017). Whereas the non-human-factors include organizational factor, as a barrier to the acceptance of new technology is cost, including implementation and maintenance costs altogether with lack of internet access in some hospitals. Some barriers could be added as legal and regulatory framework, which include Lacking of policies/ procedures that govern HIS on hospital and national levels. Technical barriers could be added which include absence of manuals or guidelines for using HIS, maintenance problems, HISs are not satisfying different users' need and data entry with data retrieval difficulties (Khalifa, 2013).

The most vital part of any information system, is the medical records, where it considered as a permanent account of a patient's illness. Their clarity and accuracy is a principal for effective communication between healthcare professionals and patients. The preservation of good medical records ensures that a patient's assessed needs are met comprehensively (Abdelrahaman & Abdelmageed, 2014).

## E. Health financing system

Health financing is the "function of a health system concerned with the mobilization, accumulation and allocation of money to cover the health needs of the people, individually and collectively, in the health system" (WHO, 2008<sup>a</sup>).

Health-care financing is one of the vital components of health systems. Most of the health sector measures attempt to address health-financing issues such as mobilization of funds, distribution of financial risks, allocation of services, and provider payment incentives. Good governance requires oversight, clear standards, and the ability to hold providers accountable, then the health systems will work, services will be delivered, and health status will improve. Poor governance undermines the quality of services and the acquisition and spending of public funds (Phua, 2018).

## F. Leadership and governance

Governance is the systematic, patterned way in which decisions are made and implemented. Governance shapes the capacity of the health system to cope with everyday challenges (WHO, 2016).

Leadership is a necessary element of strong health systems, and so it is vital to sustain leaders who can work strategically within complex environments to develop a rights-based health system that promotes health equity (Gilson & Daire, 2011).

The leadership and governance practices can influence the staff motivation and teamwork and indirectly as a consequence will affect the patient health care. Strengthening of health leadership is a wide system reform that requires intervention at individual, team and system levels (Gilson & Agyeponge, 2018).

## Chapter Three Methodology

The methodology of the study: is the way to get a relevant data to the current problem, in order to answer the research questions and resolve the research problem, including study design, study setting, study population, study sample, eligibility criteria, study instrument, data collection procedure and plan for data analysis. The analysis includes investigation of reliability and validity of the modified instrument, limitation of the study and ethical and administrative approval.

## 3.1 Study design

The research design refers to the overall strategy that is chosen to integrate the different components of the study in a coherent and logical way, thereby, ensuring the research problem to be addressed effectively; it constitutes the blueprint for the collection, measurement, and analysis of data (De vaus, 2001). Triangulation is usually used to indicate that two (or more) methods are used in a study in order to check the results of the same subject (Mertens & Hesse-Biber, 2012). The purpose of triangulation in research is to increase the validity of the results, as it is a trial to illustrate more fully rich and complex human behavior by studying it from more than single point (Cohen et al., 2000). It also gives a more balanced and detailed picture of the situation (Altrichteret al., 2005). O'Donoghue and Punch (2003), also found that triangulation of research is a method for crosschecking of data from multiple sources, to search for regularities in the research data.

Denzin (1978) identified four types of triangulation: (a) method triangulation using more than one method for gathering data such as interviews, observations and questionnaires. (b) Investigator triangulation including multiple researchers in a study (c) theory triangulation more than theory for interpretation of research data and (d) data source triangulation involves time, person and place. In this study, we are going to use the first type of triangulation by using more than one method to gather the required data.

We used a descriptive analytical approach for the quantitative research as we used a cross sectional study. Four checklists helped to identify number of the available rooms for patients and beds human resources, diagnostic equipment and the completeness of colorectal patient's medical files.

The qualitative method included three parts, key informative interviews plus colon cancer patient's focus groups and life history with selected CRC patients. The focus group method is considered relatively inexpensive; the focus group is very useful for needs assessment and project evaluation purposes (Leung & Savithiri, 2009). It also provides rapid results. Its flexible format allows the facilitator to explore unanticipated issues and encourages interaction among participants (United States Agency of International Development (USAID), 2011).

## **3.2 Study setting**

This study passed in the all of centers and departments involved in cancer control in Gaza. It is completed in the secondary health care systems, the main hospitals for providing the colorectal cancer management.

- 1. For the colorectal cancer patients' medical files, the building facilities checklists and the human resources checklists, which is done in El-Shifa hospital (the central Archive and the surgical department). In addition, the European Gaza Hospital, this included cancer outpatient clinic, central archive and surgical department, finally El-Rantisi Specialized Hospital, which included cancer inpatient clinic and central archive.
- 2. For the diagnostic facilities checklists, the data is gathered from all the governmental hospitals, the private, and the non-governmental hospitals, which are known to be concerned about the colorectal cancer diagnostic care.

Beside the secondary health care providers, the study used the facilities in the health information centers as information technology unit of MOH and Cancer Registry of the MOH as they considered of the main sources of CRC management data.

## 3.3 Study period

The study started in February 2018 and was completed in February 2019.

## 3.4 Study population

## 3.4.1Quantitative study population

1. Colorectal cancer patient's documentation files for the provided services; is a group of inpatient files to be selected from the central archives of the oncology unites and surgical

departments at (European Gaza Hospital, El-Rantisi Specialized Hospital and Al-Shifa Hospital) the completeness of the files are checked if it were properly done.

2. The diagnostic facilities: basic x-ray, basic lab, colonoscopy, CT, MRI in all the governmental hospitals and the private and non-governmental hospitals and centers which are known to provide diagnostic care for the colorectal cancer patients.

3. Cancer service rooms and cancer beds of European Gaza Hospital, El-Rantisi Specialized Hospital, Al-Shifa Hospital and El-hayat private hospital

4. The number of all health staff in oncology service, surgery, pathology, radiology service administers the cancer beds/departments in the European Gaza Hospital, El-Rantisi Specialized Hospital and Al-Shifa hospital

## 3.4.2 Qualitative study population

1. Health care providers and key informants who are involved in colorectal cancer management in MOH, private and non-governmental hospitals, the criteria depended on their positions and their roles in the colorectal cancer control

2. Colorectal Cancer patients focus groups. Those patients were selected from both the inpatient clinic and day care units in The European and El-Rantisi Specialized hospitals. Four separated focus groups of patients were held, two were done in Al- Rantisi Specialized Hospital for both genders and the other two in The European Hospitals. They were asked to participate in focus groups to discuss their satisfaction, needs and perspective toward the provided services.

3. Life history (informative interview) for the CRC patients

## **3.5 Sampling process**

## 3.5.1 Sampling for quantitative data

The researcher planned to gather data from a sample extracted from the expecting total registered CRC cases from the year of 2015-2016, which were 420 cases, but some problems were faced in the medical files availability. The researcher succeeded to reach 100 files from Al-Shifa, El-Rantisi Specialized and the European Gaza hospitals; therefore, we examined all the available files.

## 3.5.2 Sampling of qualitative data

## 3.5.2.1 Selection of cancer patients for focus groups

The CRC patients were selected from the CRC inpatient and day care clinics of The European Gaza Hospital and El-Rantisi Specialized Hospital. The researcher took in consideration the appropriate time for the first meeting.

The researcher choose two patient's focus groups for each hospital (The European Gaza Hospital and El-Rantisi Specialized Hospital) with a total of four focus groups, which effectively reflected all CRC patients' level of satisfaction and their perspective about the services received, the building design, and quality of care services.

## 3.5.2.2 CRC patients' life history

Two CRC patients were selected randomly. The researcher presented herself to the selected patients and their family and explained the goals for the research. The researcher ensured that the participants agreed to participate (informed consent). Life history approach tells the story about the research subject. Therefore, this method can provide information regarding the informant's real life. It is an opportunity to understand the social process that takes place in the informant's life at a certain time and increase the ability to approach the social and economic space of the informant (Abu Baker & Abdallah, 2008).

## 3.5.2.3 Key informants interviews

The method for selecting the key informants for in-depth interview was non-probability purposive sampling, which is based on selection of people who are engaged in the management of CRC. The purposive sampling is widely used in qualitative research is for identification and selection of information rich individuals who are the most capable to answer the research problem probably with effective us of time and resources (Patton, 2002).

The selection of the key informants was through writing a list of the key informants who are responsible and have the full knowledge on CRC management. The selection of the responsible key informants in MOH, private and NGOs was for providing the best plan for enhancing the quality of CRC management. The researcher called the key informants, introduced herself, and illustrated the aim and purpose of the study. The researcher set an appointment suitable for the key informants and ensured the key informants about the privacy and confidentiality of the study. This approach helped the researcher to get information directly from knowledgeable people and to explore the other side of the picture, provide flexibility to explore new ideas and issues not predicted during planning, they are of law cost and easy to be conducted (USAID, 2011).

Table 3.1 Number of involved key informants

Category	Number of involved key informants
МОН	11
NGOs	1
Private	3
Total	15

## 3.6 Eligibility criteria

## 3.6.1 Inclusion

## A. Selection of focus groups participants

- Colorectal cancer patients aging between 40-65 years
- Diagnosed with colorectal cancer and receiving care from cancer services at least for more than two months
- Physically and mentally wellbeing with the ability to respond

## **B.** Selection of patients for life history

The researcher selected CRC with life history related to the access, early discovering CRC and relationship between the facility and the patient.

## C. Selection of key informative person:

The researcher selected the managers who were on the top of their responsibilities and they were responsible on the CRC management for at least two year.

## **D.** Selection of patients files:

Files selection should be for patients who are receiving CRC care in 2016-2017

## 3.6.2 Exclusion criteria

## A. Exclusion criteria for focus group

- Patients who had contagious disease
- Patients who hadn't the acceptable mental capability

• CRC cancer patients who received the CRC management services less than two months.

## **B. Exclusion criteria for key informants**

- Key informants who had experience less than two years
- Key informants who didn't practice their work currently

## **C.** Exclusion criteria for patient files

- Damaged files
- Files of incomplete patient data
- Files for CRC patients didn't receive the management care from year 2017
- Files of CRC patients, which didn't present in the archive

## **D.** Exclusion criteria for diagnostic facilities

- Ultrasound (US) in Obstetrics and Gynecology Department
- Mammography
- Cardiology diagnostic services

## E. Exclusion criteria for human resources and diagnostic facility of cancer:

- Human resources who were not on top on their work
- Recent appointment (less than one year)
- All volunteers

## **3.7 Study tools**

## **3.7.1 Quantitative study**

The researcher used Adult Medical Record Review Tool — Primary Care Provider, Emblemhealth (2012) model as a checklist for evaluating the selected medical files with modifications to fit the study (Annex 3). It included several components to evaluate the medical records: patient demographic data, medical record characteristics, medication record review, physical examination and history, medications review, cancer characteristics and chemotherapy record review.

The researcher used another three checklists in Annexes (2) from Abu Amer (2012). The checklist included the information the researcher planed for covering the components for

evaluating the CRC management. The list includes distribution of rooms and beds, distribution of human resources and distribution of diagnostic facilities in the CRC providing services hospitals.

### 3.7.2 Qualitative study

Open-ended questions are prepared for the key informants (Annex 4), focus groups and for life history (Annex 5) based on related literature for the development of tool. For the focus groups, the constructor guided approximately 10 people in a discussion of their experiences, feelings, and preferences about a specific topic in community based organizations. The sessions typically last for one hour. The life history involved sequencing of life events with the most influenced CRC patients about their management journey in particular and the key informants' interviews, qualitative, interview of 15 informants who had the complete knowledge about the management of CRC. The interviews were structured depending on a list of issues discussed. Key informant interviews resemble a conversation among acquaintances, allowing a free flow of ideas and information (USAID, 2011). The areas of interest will be concentrated on the following items: The strategy planning of cancer control, quality of care, the infrastructure (human resource, building design research), information system, referral abroad and patient's needs assessment.

#### 3.8 Data collection

The data collection is started after obtaining the ethical and administrative approval; the privacy and confidentiality are maintained.

#### 3.8.1 Quantitative data

### 3.8.1.1 Medical records

The researcher conducted the evaluation of the CRC patients' medical files in El-Rantisi Specialized Hospital, Al-Shifa hospital and the European Gaza Hospital by using the selected study checklist.

### -Checklists

The other checklists are used to identify number of the available rooms for patients and beds, human resources and the diagnostic equipment.

The researcher collected the data for the checklist from the all the governmental hospitals and some of the private and non-governmental hospitals and centers in Gaza Strip are known to provide colorectal cancer management services either diagnostic or treating care.

## 3.8.2 Qualitative data

## 3.8.2.1 Focus groups

The researcher conducted two focus groups one in the European hospital for both males and females groups and the other in El-Rantisi Specialized Hospital for both males and females groups. Each group had discussion on their needs, satisfaction and their perspective and the quality of the received care.

The researcher presented herself to the patients; explained the goals for the research and the importance for their enrollment in the research as their opinions will be a tool for improving the health services provided for the CRC patients. The researcher ensured that all the participants agreed to participate (informed consent). The researcher confirmed the confidentiality and privacy of the given data.

The interviews schedule contained questions that were brief and reasonable. The interviews were conducted in a private relaxing environment. The researcher decided the place for meeting the focus groups, as it is quiet, accessible, neutral, secure and comfortable after selecting the participants for focus groups and it was held four times.

Open-ended questions are used to allow the participants to tell their story in their own words, using probing techniques, controlling the discussion by giving nonverbal cues and minimizing the group pressure. Tape recordings in conjunction with the written notes are useful, shortly after each group interview, the team should summarize the information, the team's impressions, and implications of the information for the study (USAID, 2011)

Each FGD was 8-10 CRC patients, the groups are encouraged to participate and give their opinion in an interactive conversations that included questions like:

- Opinion about the CRC management service quality.
- Barriers preventing them from accessing the service.
- Perspectives, Ambitions and needs.

#### 3.8.2.2 Life history

The researcher will conduct sequencing of CRC management events with the most influenced CRC patients, displaying the events (diagnosis and treatment) in chronological order and noting the importance, or meaning, of events. The sequencing highlighted the important events in CRC management.

#### 3.8.2.3 Key informants

The data from the key informative person's interview was conducted in a place preferred by the key informant after explaining the purpose of the interview, the intended uses of the information and assurances of confidentiality and privacy. The interview should be started by factual questions followed by questions requiring their opinion and judgment by using probing techniques. The data was collected through audio recording and researcher note was taken, and the transcript was done as soon as possible after the meeting (USAID, 2011).

#### 3.9 Data Analysis

### 3.9.1 Quantitative data analysis

The study analysis was begun first with development of a model through Statistical Package for Social Sciences (SPSS) for data entry, and then was followed by several steps; checking and verifying the collected data from having errors as missing or inconsistent data. The next step was the entry of data through the mode was prepared, data cleaning and then the processing of this refined data was established. SPSS program version 20 was used as statistical programs to analyze the obtained quantitative data. Each item of the CRC patient's medical records was assessed through frequency tables. Numbers and percentages presented the results through the used tables in the result chapter.

#### 3.9.2 Qualitative data analysis

The researcher obtained the main findings from the audio recordings of the key informant interviews and focus group. The data management was started with deep reading of the raw data brought from the transcripts.

The notes were taken to identify the important items, which are concerned about cancer control, quality of care, infrastructure, referral abroad and patient perspective. The researcher then started with the axial coding through the disaggregation of core themes

during qualitative data analysis. Axial coding is a qualitative research technique that done by relating data together in order to reveal codes, categories, and subcategories ground within participants' voices. In other words, axial coding is one way to construct linkages between data (Allen, 2017). Axial coding has a historical relationship with grounded theory, which is a qualitative methodological framework that involves constantly comparing emergent themes within one's data set in order to make theoretical claims regarding one's communicative conduct (Strauss & Corbin, 1998). The researcher displayed the important data in a way that the interpretation became understandable; the process was to reconstruct the data in a meaningful or comprehensible fashion.

#### 3.10 Scientific rigor

## 3.10.1 Quantitative research

A special attention was given to improve the validity of the quantitative part of the study; which means the tool used in the study conduction is actually measuring what is intended to measure (Fathallah, 2004). The study validity to be improved and to have a more adequate tool required for the study conduction; several steps are applied to ensure the study validity:

The content (construct) validity means the degree to which a test measures what it claims, or purports, to be measuring (Brown, 1996); adequate reviewing of related topics in literature about management of CRC was performed before designing the study and its tool, beside reviewing some of already prepared tools related to the topic (Lafaille & Wildeboer, 1995). Content validity should focus on the content of the test. To demonstrate content validity, testers investigate the degree to which a test is a representative sample of the content of whatever objectives or specifications the test was originally designed to measure. To investigate the degree of match, test developers should enlist well-trained colleagues to make judgments about the degree to which the test items matched the test objectives or specifications (Brown, 1996).

Whereas regarding the study reliability which means the overall consistency of a measure (Trochim, 2006). The following steps performed to improve the reliability: The data collector was trained to standardize the data collection method; the obtained data was checked over the time of the work. Data reviewing if being missed or inconsistent before analysis took place and reentry of the data was done to test the accuracy of its entry.

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#### **3.10.2 Qualitative research**

The concept of reliability and validity are substituted by data trustworthiness. Trustworthiness of qualitative data will be obtained through assuring following many steps: (a) Credibility: confidence in the truth of the findings (b) Transferability: is the generalization of the study findings to other situations and contexts. (c) Dependability: the findings are consistent and could be repeated (d) Confirmability: the researcher is neutral; the findings are shaped by the participant and not researcher bias (Devault, 2017).

Several techniques are used in order to increase credibility in a qualitative study as:

- (a) Pilot key informant interview and pilot focus group: the researcher did a pilot trial for the key informant interviews and the focus groups. This allowed the researcher to assure the suitability of the questions, the understanding of the asked question and to measure the required time for the interviews and the focus groups.
- (b) The researcher begin writing early, the researcher used to analyze the key informants interviews and the focus groups directly after finishing them. This allowed the researcher to memorize voice tones, facial expressions, body reactions and the general discussion environment. This enhanced the transparency and reliability of the results.
- (c) Triangulation: is often used to indicate that two (or more) methods are used in a study in order to check the results of the same subject (Rothbauer, 2008), where the researcher try to view the research problem from many angles by engaging several methods of data collection.
- (d) Prolonged engagement refers to spending extended time with respondents in their native culture and everyday world in order to gain a better understanding of behavior, values, and social relationships in a social context (Given, 2008). As the researcher use to ask some of the question in different way to assure that the participants understand the meaning of asked questions in depth for the most appropriate answer to the asked question.
- (e) Peer debriefing also called analytic triangulation, is the process whereby a researcher calls upon a disinterested peer—a peer who is not involved in the research project—to aid in probing the researcher's thinking around all or parts of the research process (Given, 2008). Here the researcher asked two experts to review the open-ended questions, which the researcher prepared previously for the

interviews with the key informants and the focus groups. This step was essential to enhance the quality of the questions and assure that it will get the required answers for the research study.

- (f) Audit trial: the researcher described the research methodology through this chapter to assure the transparency of the research steps. In addition, the researcher kept all the records the tapes, the transcript, and field notes for the key informant interviews, the focus groups, and the product of data reconstruction.
- (g) Member checks: **informant feedback** or **respondent validation** is a technique used by researchers to help improve the accuracy, credibility, validity, and transferability (also known as applicability, internal validity or fittingness) of a study (Yanow et al., 2006). The researcher tried to check each research step with the supervisors.

### 3.11 Piloting

Pilot study is a preliminary research conducted to test elements of the design before an actual formal data collection. The piloting is needed for further improvement of validity and reliability of the study through consultation with experts to check and evaluate the items question of focus group colorectal cancer patient, in depth CRC patients' interview and key informant question and the items needed for evaluating the CRC patient's medical records. Pilot medical records, focus group, CRC patients' in depth interviews and Pilot key informant interview were done. Collected data from the piloting sample was reviewed and examined to check the ability of the open-ended questions for the patients' focus groups and the key informants' interviews to achieve their purpose. The obtained quantitative and qualitative data then were analyzed.

#### 3.12 Response rate

The response rate was very high among the key informants despite their workload. The researcher found that all the key informants are motivated with the thesis title and hope to do anything to improve the colorectal cancer management situation especially in prevention & screening activities. Moreover, they hope to benefit from any chance to send their voices & their recommendations to the concerned people to understand the current situation of colorectal cancer management in Gaza and try to change it to better situation to decrease the number of diagnosed cases in late stages and to treat the diagnosed cases effectively.

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In contrast, the response rate among the cancer patients was very low, the researcher found a difficulty to influence the cancer patient to participate in the focus group. They justify that by physical or cultural reasons especially the women.

### 3.13 Ethical and administrative considerations

Ethical and administrative approvals that are required for the study conduction were gathered and approval letters were sent to the general director of the hospitals. Ethical consideration represented by the approval of Helsinki Committee and the informed consent. The administrative approval represented by the approval of the directorate of hospitals for cancer services in Al-Shifa, El- Rantisi Specialized Hospital, the European Gaza Hospital and the rest of the governmental hospitals in Gaza Strip. Preceded by the Ministry of health through the department of the Human Resources development in the ministry was obtained before conducting the study (Annex 7). Helsinki commitment as shown in Annex (6) is to ensure the participants safety during the performance of the study. Approval letters were sent to all the private and non-governmental hospitals and centers known to provide colorectal cancer management services. All the participants received sufficient information about the goals of the desired studied topic and the procedure of data collection to encourage their participation, with assurance of their confidentiality and privacy. Files manipulation was performed delicately to prevent any damage or loss. Privacy was maintained in the data collection, reporting, analysis and sharing the findings with others who are interested such as managers and associations who may get maximum benefits of the research.

#### **3.14 Limitation of the study**

- Sample selection of colorectal cancer patients; which was complex to some extent, due to less adequate and less organized services of oncology in Gaza Strip.
- Files had missed and less accurate data including contact address of the patients
- Inaccurate ICD-O3 for the medical files, as there were many medical files were classified as colorectal cancer disease and they were not.
- Poor handwriting of the physicians made it difficult to read it and fill the medical files evaluation checklist
- Limited local colorectal cancer information and scarcity of oncology studies in the Gaza strip were an additional problem.

- The study was not considered patients who did not receive the medical services through governmental facilities. Others who did not come to the governmental hospitals might have different views and opinions.
- The physical and psychological condition of the patients represented a barrier to convince the colorectal cancer patients to participate in the focus groups, In addition, gathering them at the same time represented another constrain due to their differences (their work, social life and medical conditions).
- Cultural barriers especially for women's participant, the researcher took the approval of the patient's husband to enable her to participate in the focus group.

## Chapter Four Result and findings

The performance of the Palestinian health care system has been influenced obviously by the complex political situation, which is augmented by the geographical separation between the West bank and Gaza (Abu-Zaineh et al., 2008). The Palestinian health care system was known for a long period to be fragmented and under- financed (Hamdan et al., 2003).

The evaluation of the health care system is one of the main steps needed to identify the weak points. This study comes as an extension of the previous efforts; it is represented by the evaluation of colorectal cancer management in order to introduce information that can help the health provider to control the colorectal cancer burden.

The chapter presents the results of the quantitative and qualitative data obtained in this study through using the WHO blocks of health care system and it is effect on the management cycles starting from screening and ends in follow-up. The researcher used the qualitative data, to clear some points about colorectal cancer management strategies in Gaza Strip and to discover where the gaps and weak points are in reality by recording attitudes, behaviors and feelings.

The results showed some agreement between the key informants about the colorectal cancer management strategies, contradiction either between key informant persons and patients or between the patients themselves. The contradiction is likely related to the different expectations of both patients and key informants, the position of the key informant, the type and the stage of cancer, which naturally has different impacts on the patients that mainly depend on the method of diagnosis and treatment and the place where the patient starts and ends his treatment journey.

#### 4.1 Health workforce

WHO (2016) found that 57 countries have an absolute shortage of 2.3 million physicians, nurses and midwives. The shortage suggests that many countries have deficient number of medical staff and this is considered a main barrier to deliver the essential health interventions. WHO suggest that government and donor organizations should increase financial support of health-care workers as a means of improving the recruitment percentage. In countries with limited resources, cancer care can suffer from extreme limitations of human resources and physical capacity leading to increase the mortality to incidence ratio by 19% higher than that in industrialized countries (Rosenblatt & Zubizarreta, 2017).

Since all health care is totally delivered by and to people, a strong understanding of the human resources management issues is essential to ensure the success of any health care program. Human resources initiatives are essential in many health care systems, and more comprehensive researches must be conducted to bring new human resources policies and practices that will benefit people around the world (kabene et al., 2006).

Clearly, Gaza suffers from human resources shortage; as shown below by table (4.1) and the unified agreement between the key informants that the shortage in the human resources constitutes as a main barrier in colorectal cancer management.

Through using the table (4.1) below, it appeared that there were only seven oncologists in Gaza (0.49 per 100,000 populations). This is considered very low comparing with the international ratios. As the oncologists in Africa are 0.1 per 100,000 populations, 2 per 100,000 in Eastern Mediterranean and 3 per 100,000 populations in Europe (Alwan, 2001). This compares with 1.4 per 100,000 in Australia and 3.5 per 100,000 in the United States and 0.7 per 100,000 populations in Irland. Where, The National Cancer Control Program (NCCP) in Ireland recommends 1.8 medical oncologists per 100,000 populations (NCCP, 2014).

Through 2010, in United States 5.7 pathologists per 100.000 populations (Association of Professional and Executive Employees, 2017). The Australian Capital Territory had the highest ratio of clinicians in 2016 with 7.5 per 100,000 populations (Australian Government Department of Health, 2017). When comparing Gaza with such international

ratios, we found that Gaza has only 0.5 pathologists per 100.000 populations, which counts to be very low when compared to the international ratios.

Regarding the private hospitals dealing with cancer services, only El-Hayat hospital is proposed to deal with cancer patients completely, starting from diagnosis and ended with chemotherapy treatment. It supposed to cover the entire journey that cancer patient need in one place with proposed number of human resources to cover the entire journey from diagnosis step to treatment and follow-up steps with same physicians working in the governmental hospitals. There will be no clear split between Al-Hayat hospitals oncologists and the governmental ones as viewed by table (4.1) below.

For the GPs number in the oncology departments, there is only one GP, which is considered a major gap for the oncology departments. This may show the negligence of the MOH to the oncology department, and prevent the training dimension of such fresh graduates. Regarding the number of surgeons in Al-Shifa hospital, they are 43 general surgeons in three departments, from the total they are only nine surgeons who are qualified to do colorectal tumor surgeries, when compared to the European Gaza hospital it has only 19 general surgeons with no specialization.

We have no any nutritionists in the hospitals cared about the colorectal cancer or cancer in general, which is considered weak point for the hospitals caring about the cancer in Gaza Strip, as good nutrition and nutritional therapy are important for cancer patients before, during and after treatments. Good nutrition seems to have beneficial effects on the oncological therapy. So close collaboration between doctors and nutritionists is needed (Ose et al., 1998). Despite Psychosocial intervention is a cost-effective approach that can improve a patient's mood and quality of life both during and after radiotherapy (Guo et al., 2013). We do have only one psychologist in the hospitals caring about cancer patients in Gaza Strip.

 Table 4. 1 Distribution of human resources serving cancer services in the three governemtal hospitals (El shifa, European Gaza and El-Rantisi hospital)

Categories	El-Shifa hospital		European Gaza Hospital		El-Rantisi hospital		Total		Al- Hayat hospital	
	М	F	М	F	М	F	М	F	М	F
Oncologists	-	-	2	1	4	-	6	1	4 (3)	-
Surgeons	42	1	19	-	-	_	61	1	(6)	-
GPs	-	-	_	(1)	-	1	-	1(1)	(6)	-
Nurses	-	-	16	14	14	14	30	28	(6)	(6)
Radiologists	5	3	5	1	3	-	13	4	(1)	-
Pathologists	3	1	-	1	-	-	4	1	(2)	-
Psychosocial	-	-	-	-	-	1	-	1	(2)	-
Nutritionist	-	-	-	-	-	-	-	-	(1)	(1)

The numbers between brackets are part time workforce

Al- Hayat hospital: Officially not opened and the numbers are approximated

Apparently, Gaza suffers from human resources shortage; as there was a general agreement between the key informants that the shortage in the human resources constitutes a main barrier in cancer control. This was noticeable in the sentences of the key informants. As a chief surgeon said, "We have good human resources, but not adequate, there is a big shortage in the quantity of specialized oncologists, colorectal cancer specialized surgeons, cancer specialized nurses, social worker, psychiatrists and cancer specialized nutritionists". Another chief surgeon added, "For sorrow the cancer specialized human resources scarcity is a subject that doesn't discussed before in MOH" and he completed his sentence with angry voice and said, "The size of the problem is huge, and needs a rapid solution".

A surgeon said, "Colorectal cancer" يدق ناقوس الخطر" as it became the first cancer in males in a short period, so we need a multidisciplinary team to deal with such a danger". A private hospital owner talked with sorrow, "We have a huge trouble in the health care system as any general physician is sent to the oncology department despite that it's the most dangerous department and cost the MOH about 60-70% of its financing". An oncology consultant added, "The human resources in the oncology departments are insufficient because of increased number of cancer cases, also the MOH doesn't pay attention to the oncology departments at all".

Moreover, a chief oncologist explained, "MOH doesn't provide any special attention to the oncology departments, where we are awaiting to any general practitioner to teach him, but for sorrow we doesn't meet them". Where he added, "At least we should be 10 oncologists in European Gaza hospital, we reclaim again and again to improve the number of human resources for oncology services, but no one hears us or meets our requirements". He also clarified his talk, "We always hear about foreign external medical delegations visit the variable departments, but we never hear about foreign oncologist delegation".

The head of nurse department show his dissatisfaction about the current shortage in the number of nurses as he said, "Actually we had shortage in the nurse numbers in the oncology department, but we try our best to cover this shortage, the actual non-covered shortage is in the oncologists"

A chief surgeon added another dimension for the human resources as he talked about gender based treatment, "The problem for female patients, that they need female surgeons to deal with them, but the problem we haven't any qualified female surgeon, so the case will be referred to us with complications after non-qualified surgical intervention"

In addition, a surgeon said, "We don't have surgery specialized departments in Gaza, we are all just general surgeons. I succeeded in adding the procto-surgery term in Al-Shifa hospital, but we still needed a colorectal department, with centralization of services to be provided to such colorectal cancer patient, the problem in instituting such department is the fear from decreasing the number of patients went to the private surgeons which is a selfishness (أنانية) for the surgeons"

As it appeared by the obtained results in table (4.1), there is a significant shortage in the number of pathologists. As mentioned by main pathologist, "As the pathological department at Al-Shifa Hospital is considered as the largest department of pathology in the Ministry of Health and the private sector, which receives at least 5000 cases annually, which is a large number when compared to the number of employees in the department". Through the table No. 4.1, it appeared that the number of histo-pathologists in governmental hospital of Gaza was only five distributed as four in Al-Shifa hospital and one in Gaza European hospital.

From the collected data (qualitative and quantitative), there is an evident shortage in human workforce related to oncology services as viewed in table (4.1).

Where this shortage also manifested in the radiology departments, as majority of the interviewed key informants talked about the shortages in oncology specialized radiologists doctors. One of key informants said, *"The radiologist doctors who are able to read magnetic resonance imaging are counted on fingers, their number is very limited"*.

About the psychologists and social workers, the majority of key informants agree that we have a serious defect in this area, as some of the key informants explained, "Social working in our oncology departments is a catastrophe; we have a big defect in this area as it's not found". Some added, "Such poor patients need to talk, we need truly the psychosocial workers to start strongly their work".

In addition, the problem is appeared when we talk about the oncology specialized nutritionists, as all the key informants agree on its absence from our hospitals.

The participants in the focus groups show their dissatisfaction about the shortage in the number of oncologists and added that this shortage affect the quality of the received care as they said.

"Every time I hope to have my sufficient time to discuss my disease with my oncologist and to answer some questions rose in my head, but unfortunately I can't have the chance because of the overcrowdings of patients and limited number of oncologists"

In addition another said, "I spent two days in the inpatient department waiting my Dr. to come to see me, but he didn't come, this is because he can't bear the overload, my Allah gives them the help (الله يعينهم على هما فيه)"

"No one discuss with me to where I have reached in my treatment journey"

Moreover, some of participants comment on the disrespect they found in the inpatient clinic as some of them said,

"All I need is respect; I don't need my treatment if no one respects me".

"Why did the nurse XX shout on me and prevent me from seeing my Dr. XX after finishing my chemotherapy dose?"

## "The nurse XX shout on me despite I'm older than his father"

When the patients are asked about the presence of psychologists and nutritionists in the inpatient departments, some of them said that they did not see any of them. Four of them only said that they saw only a psychologist once only and she was a volunteer, they said that her advices were useful to them and hope to see her every time they are admitted to the department.

Moreover, the female participants in the focus group show their dissatisfaction about the shortage of women medical staff especially at night as they requested to cover this gap and asking to employ more women in the services.

In conclusion, the shortage of human resource not concern only the oncologist but include also the onco-surgeons, oncology specialized nurses, psychiatrics, pathologists and nutritionists and mainly were related to the underinvestment of health workforce.

#### - Training and scholarships:

The problem of human resources shortage is augmented by the absence of training and scholarships offered for the workforces worked in oncology departments, as it appeared evidently by the response of the key informants. As a chief oncologist when asked about training he answered with blaming voice, "MOH doesn't provide any training course or scholarships for any kind of workforces in the oncology departments". Where a chief surgeon added," The quality of surgeon should be raised by intensive courses for laparoscopic colectomy surgery as it is deficient entirely in Gaza".

A consultant surgeon commented by, "We have no training at all, the general idea we have, that senior surgeon trains his staff on what he knew, but we don't know whether the training is right or not, we have no supervision on this form of training". And he added, "Internationally, laparoscopic colectomy is the mainstay for surgical treatment of CRC. But locally we still use open colectomy, with no training courses on such option of treatment, we are only waiting for foreign delegations once every 6 months, to operate only one case during their stay, which is not enough at all".

A colorectal surgeon talked with sorrow about this issue, "The scholarships are an effort totally payed by the surgeon, because he wants to develop his knowledge, without any partial support from MOH". Another surgeon added, "As a surgeon I need from time to time to go outside for either training courses or scholarships with self-cost-driven, but as we are governed by many external factors as a siege, then the issue will be so hard, then we are deprived from such opportunities".

Where a private key informant found a solution for the overload on the oncologists by the training of new graduates as she said, "We should have surviving clinic, two fresh graduates to be trained by the oncologists consultants to hold the surviving clinic, then the load will be released from the oncologists to see only newly diagnosed patients. The patients overload should be divided to decrease the tension. A clinic for patient to be referred should be added"

A chief pharmacist added, "We are in small siege, can't have the simplest right which is training or scholarships abroad, this can prevent us from improving our qualifications"

The head of nurse department show his displeasure when we talked about the training as he said, "I try to train my nurse team, and no one respect this, when I talked about this, the MOH refused and they said you should send an approval letter for the MOH to approve this activity. No one could restrain me from improving the skills of my team! ( هادا الله )" (هادا فریقی و بدی اناقش معه الحالات

As it appeared from the responses of the key informants, the training and scholarships represented a vital corner in the management of colorectal cancer discussed point from most of them; we can consider this as an important step to improve colorectal cancer management in Gaza especially in some specialization of colorectal cancer surgery, oncology, palliative care and pathology.

#### 4.2 Service delivery

#### 4.2.1 Building

The efficient allotment of health care resources in health care infrastructure is the most terrible question in the health policy. Availability of healthcare infrastructure –defined as distance to specialty treatment centers, specialization of hospitals- is an essential prerequisite for the use of health care resources, and the problem of decision makers is to determine if an investment in more healthcare infrastructure will result in better outcomes (Blankart, 2012)

The literature enhances the significance of this vital sector as mentioned by Zimring et al. (2004) who insure the presence of a positive relation between the building design and the patient physical and emotional outcome as it could help to decrease medical errors and human resources stress in addition to improve sleep and to reduce pain.

Despite the importance of building quality and design in cancer management in general, most of cancer service sites in Gaza are inappropriate and unhelpful to implement controlling the cancer as viewed below by the table (4.2) and the agreement of the majority of the key informants.

Through using the checklist (Annex no. 2) concerning the number of rooms, we found in Al-Shifa department zero rooms for the inpatient service zero halls for the day care as the cancer care totally transferred to El-Rantisi hospital in 2006. In European Gaza hospital, we found seven rooms for inpatient service with total 17 beds, and four rooms for daily care with 9 beds and 20 chairs. Concerning El-Rantisi specialized hospital, we found twelve rooms for the inpatient care with 30 beds and two halls for the daycare clinic with 8 beds and 16 chairs. For the non-governmental hospitals, only El-Hayat hospital, which is classified as private hospital, although physically it is present, but it is not functioning yet due to administrative and financial problems. The oncology department is proposed to open his doors provide inpatient cancer and day care services for cancer patients in 2018, it composed of 9 rooms to provide inpatient service with 19 beds and 1 hall to provide the day care with 8 chairs and 6 beds for critical cases. In total, we can count that cancer services in Gaza for the governmental hospitals contained 19 inpatient rooms with 47 beds serving the admitted cancer patients, 17 beds, and 6 rooms for the day care with 49 beds and chairs. In addition, when El-Hayat hospital starting to receive cancer patients, the number of inpatient rooms will be raised by nine rooms to reach 28 rooms with 66 beds and day care halls will be raised by one hall to reach seven halls with 63 beds and chairs to receive day care management. The results are shown below in table 4.2.

We found that Gaza has only 0.04 beds per 1000 populations for the oncology departments. In parallel in 2015, for the total hospital beds in occupied Palestinian territories have 3.03, Turkey 2.68 and France 6.18 beds per 1000 populations (Organization for Economic Co-operation and Development (OECD), 2019<sup>a</sup>).

Hospital	-	ent care ard	Day	care ward	Comments
nospital	No. of	No. of	No. of	No. of beds	
	rooms	beds	rooms	& chairs	
Al-Shifa hospital	0	0	0	0	Under construction
El-Rantisy hospital	12	30	2	20	Temporary host adults
European Gaza hospital	7	30	4	29	
Total	19	60	6	49	
El- Hayat Hospital	9	19	1	14	Not opened yet

Table 4.2 Distribution of oncology rooms and beds

The key informants also support the mentioned above findings vigorously about the inadequate, unsuitable, inappropriate buildings design for oncology services in the main hospitals providing the oncology services. As a chief surgeon described the sites for colorectal cancer treatment as "mass production sites with no respect to the privacy or the humanity of the patients". Another chief surgeon expressed his disappointment saying sadly, "our hospitals as a whole aren't good enough to receive all patients". A third surgeon added " It's for a sorrow, that such patient has enough from his disaster, his disease, so he needs a five stars center to start his journey within it". A consultant oncologist added, "The building quality in both oncology centers doesn't meet patients' needs or requirements, don't respect the privacy or humanity of such poor patients". Where he added, "because of the limited number of inpatient rooms, we found an oncology patient dying next to oncology patient starting his treatment journey, and then this patient will have an idea that he is dying (أنا موات) for sorrow". In addition, a key informant added, "We need to convert the inpatient rooms' services from MOH to the private sector in means to be hotel services to meet the cancer patients expectations". Where a senior oncologist added, "Our oncology centers in both El-Rantisi and European Gaza hospitals are needed to be reconstructed as soon as possible". Another key informant added, "How did they establish a cancer adult department in a hospital deals with the pediatric specialties? It's unreasonable!"

A consultant oncologist talked with sad voice, "The building quality is very bad in the oncology department in the European Gaza Hospital, the water pipes leak on the walls, so for sorrow we have moldy walls in the inpatient rooms". And he added, "Patients will be delayed, as we don't have empty beds in the day care for their chemotherapy treatment"

A private hospital owner described the main hospitals providing colorectal cancer management, "There is no understanding to the psychological aspects of the cancer patient when designing the cancer units, even wall painting should be according to standards to relieve the patient distress, but nothing is taken in consideration". In addition, he added, "our hospitals are the sites where cancer patients wait their death".

A private key informant think about the quality of building of the oncology centers for the workforces as she said, "MOH should make an oncology center separate from all the governmental hospitals, why the nurses and pharmacists are stuffed in a tight place, they are very tired (مهدود حيلهم على فكرة)". And clarified her talk, "The building quality, design, hospital environment are very bad"

Regarding the pathology unit building in Al-Shifa hospital, a chief pathologists said, "Regarding the place where we are working, is not suitable for the working environment, and is not enough, we are promised to shift to another site, but the subject is suspended since a long period of time".

Regarding the pharmacy in Al-Rantisi hospital, a chief pharmacist said, "The pharmacy in Al-Rantisi hospital reached this accepted level, by our personal efforts not the Ministry's efforts. The pharmacy as a whole was only one room; by our efforts, we expanded the pharmacy to two rooms with (pass through chamber), to decrease the contamination level. We produce what is known as pressure difference between the two rooms according to the international criteria"

In addition, he added, "We are waiting an extraordinary change in the adult oncology services; as Palestine Children's Relief Fund (PCRF) established a pharmacy in the child oncology departments and we made an agreement with the PCRF to serve also the adult oncology department and this is a golden chance for the adult patients. The established pharmacy is nearly the same as the pharmacy in the MD Anderson Oncology Centre. Air pressure difference, air motion and all the requirements were requested have been met, So that it satisfies everything related to the safety of the patients, the pharmacist who prepare the chemotherapy doses and to protect the environment".

Moreover, he clarified his talk with a sad voice and said, "The pharmacy was established by the PCRF is supposed to be started in 2015 and now we are in 2019 and nothing happens. There were promises to start in the last January and now we are in February and the pharmacy has not been started yet. The only obstacle is the crossing borders, because the building materials and gas pipelines need the approval of Israel. Everything is hard in Gaza. Everything is prohibited; equipment, diagnostic devices, therapeutic devices and even patients".

The head of nurse department talk about the squeal of the inappropriate narrow building in Al-Rantisi Specialized hospital as he said, "Because of the narrow space in the oncology department in Al-Rasntisi hospital for the oncology patients. We sent our patients to other departments in other hospitals, and the problem started here, where the other doctors are afraid from the name of cancer patient, where they can't deal perfectly with the cancer patients"

On the other hand, the collected data from the participants in the focus groups done in the European Gaza hospital are matched with findings from the key informants, their dissatisfaction was clear for both the inpatient rooms as they said:

"The inpatient rooms are very few; that sometimes you can have your treatment in other departments and other times my treatment is delayed to another week, because there is no enough beds for patients"

"The inpatient rooms here in the European Gaza hospital is much better than Al-Rantisi hospital, where there are 4-5 patients in one room, which is a disaster"

"I received my last dose in the female oncology department, which was embarrassing because of insufficient beds in the male oncology department"

"When the chemotherapy doses were recommended to me, and I started my first dose of chemotherapy, they put me beside someone who is dying, as they told me this is your way (إنت على طريقه)"

Where other participants added their comments with angry voices on the inpatient clinics as they said:

"In inpatient clinic, there is no space, there is no enough chairs to sit ( الواقفين أكتر من الي ), it's an overcrowded space"

"The inpatient clinic has no proper air conditioning or lightening"

"The Palestinians are poor (الشعب الفلسطيني غلبان), they agree and accommodate with any situation"

"I stood waiting my turn to enter to Dr. XX for more than half an hour in the inpatient clinic till I felt dizziness and fell down"

Some of the participants talked about their needs to solve such a problem as they said,

"We need privacy, as after the chemotherapy dose we can vomit, and this is embarrassing in front other patients and their relatives"

"We need a big hall for the inpatient clinic as all the poor persons are standing, which is unbearable, My Allah resolve the situation (الله يفرجها علينا بس)"

In the other hand, a participant talked negatively about any solution in the current future as he said,

*"Even if they built another building beside this one, the problem will not solved because of the uncontrollable increased number of patients"* 

Regarding Al-Rantisi Specialized hospital, the patients were totally unsatisfied with the inpatient department as they said,

"My chemotherapy doses are delayed always for 3 days after my appointment, because there was no space!"

From the collected data from both the key informants and the participants of focus groups; we can conclude that the oncology service in Gaza are inadequate and have a lot of defects, especially the limited number of rooms and chairs which lead to overcrowded rooms. As consequence, this can reduce the privacy and comfort, and increases the noise, bad aeration, distress and cleanliness. Moreover, the building design for pathology and

pharmacy departments, is inadequate and do not obey the optimal requirements. These factors are considered a barrier for service delivery.

## **4.2.2 Diagnostic facilities**

Diagnosis has important implication for patient care, research and policy where it involves initial information collection that leads to diagnosis. Diagnosis has been described as both a process and a classification scheme, or a "pre-existing set of categories agreed upon by the medical profession to designate a specific condition" (Jutel, 2009). Advances in biology and medicine have led to improvements in prevention, diagnosis, and treatment, with a cascade of creations in diagnostic testing (Institute of Medicine, 2000).

## - Diagnostic facilities shortage

Access to the efficient number of the diagnostics services is essential for ensuring rapid disease diagnosis, management, control, and surveillance and this can improve the health care outcomes and aid the timeliness and accuracy of medical decision-making (WHO, 2013, Peter et al., 2010).

Through using table (4.3) and (4.4), the researcher tried to estimate the availability of some equipment and diagnostic facilities necessary in colorectal cancer diagnosis.

	Imaging techniques								
Hospital	X-	US	MRI	CT	Fluoroscopy	Gamma	Linear	Colonoscopy	
iioopiuui	ray	ray 0.5 Will scan rubioscopy camera accelerator Governmental hospitals							
Abu Yousef	Governmental nospitals								
Al-Najjar	3	1	0	0	0	0	0	0	
hospital	5	1	Ŭ	Ū	Ū	Ū	Ū	Ū	
Al-Aqsa	•		0	1	0	0	0	0	
hospital	2	4(2)	0	1	0	0	0	0	
Al-Shifa	1	$\zeta(\mathbf{F})$	2(1)	2(1)	2(1)	1(0)	1(0)	2	
hospital	1	6(5)	2(1)	3(1)	2(1)	1(0)	1(0)	Z	
European									
Gaza	2	2	1	1	0	0	0	2	
hospital									
Indonesian	1(0)	2	0	1	0	1	0	1(0)	
hospital	-(*)	_	-	-		_		-(-)	
Nasser	2	2	0	1(0)	0	0	0	1	
hospital									
Rantisi specialized	1	1	0	1	0	0	0	0	
hospital	1	1	0	1	0	0	0	0	
nospitai			l	Р	rivate hospitals	and cente	rs		
Ajjour center	0	2	0	0	0	0	0	0	
Al-Hayat									
hospital	1	2	0	1	0	0	0	1	
El-Helou	1	3	0	1	0	0	0	1	
hospital	1	5	0	1	0	0	0	1	
Gaza scan	1	1	0	1	0	0	0	0	
center	1	1	Ŭ	1	0	0	0	•	
Palestinian					0				
German	1	0	0	0	0	1	0	0	
center			G	. 0 N		11 41	1 /		
A1 A11:			Sem	1 & NO	n-governmenta	l hospitals	and centers		
Al-Ahli bospital	1	3	0	0	1	0	0	2	
hospital Al-Awda									
hospital	4	4	0	0	1	0	0	1	
Al-Quds						-		-	
hospital	2	4	1	1	0	0	0	2	
Patient's									
friend	1	3	0	0	1	0	0	1	
society									
Public aid	1	2	0	1	0	0	0	2	
hospital	1	4	0	1	0	U	U	۷	
Red Crescent	1	1	1	1	0	1	0	2	
society	-	-			\$			-	
Total									
number of	25	39	4	11	4	3	0	15	
working devices									
Numbers betw		oolaata i	ndiaat			ut of the o	voilabla		

 Table 4.3 Distribution of imaging techniques through GS hospitals and centers

Numbers between brackets indicate working devices out of the available

	Laboratory techniques								
Hospital	CBC	Chemistry	Occult blood tests	Tumor marker					
	Governmental hospitals								
Abu Yousef Al-Najjar hospital	2	2 (1)	0	0					
Al-Aqsa hospital	4 (3)	3	0	1					
Al-Shifa hospital	9	2	0	0					
European Gaza hospital	4	2	0	0					
Indonesian hospital	4	5	4*	0					
Nasser hospital	3	3	0	0					
Rantisi specialized hospital	3	2	5*	0					
	Private hospitals and centers								
Ajjour center	0	0	0*	0					
Al-Hayat hospital	1	1	0*	1					
El-Helou hospital	2	2	1*	1					
Gaza scan center	0	0	0*	0					
Palestinian German center	0	0	0*	0					
	Semi & Non-governmental hospitals and centers								
Al-Ahli hospital	2	2	0*	0					
Al-Awda hospital	2	1	3*	1					
Al-Quds hospital	2	3	15*	1					
Patient's friend society	2	2	2*	1					
Public aid hospital	2	4	20*	1					
Red Crescent society	3	2	4*	1					
Total	44	62	54*	8					

Table 4.4 Distribution of laboratory techniques through governmental, private, semi-<br/>governmental and non-governmental hospitals and centers

• Numbers between brackets indicate working devices out of the available

• Numbers marked by a star indicate number of occult blood tests per month

Comparing the availability of CT and MRI in neighbor country we found that in 2012 the number of CT in Lebanon is 110 (24.8 device per million population) while the number of MRI devices is 41 (9.2 device per million population) (Ministry of health of Lebanon, 2014). There is no general guideline regarding an ideal number of CT scanners or MRI units per population, if there are too little such items of equipment, this may lead to access problems, either in terms of geographic proximity or waiting times.

There are only four MRI devices, two in the governmental hospitals and two in the nongovernmental hospitals (2 MRI devices per million populations), which is considered low when comparing this ratio with international ones, we found in occupied Palestinian territories 5.17, Turkey 10.55, United States 37.5 and Japan 51.69 MRI device per million populations (OECD, 2019<sup>b</sup>). Where PET scan is, absent from all hospitals in Gaza Strip.

For CT devices, we have eight devices in the governmental hospitals, 5 of them only working and six devices in private and non-governmental institutions with a total of 12 working devices if we added the CT device in Al-Salam center in Rafah. We have 8.9 CT devices per million populations for all hospitals and centers, which is in parallel with the occupied Palestinian territories as there is 8.7 devices per million populations, but when compared with international ratios we found that we have less than international ratios. As for United States, there are 27.09 and France 12.36 CT devices per million populations (OECD, 2019<sup>c</sup>).

They key informants comment on the shortage of diagnostic facilities especially the colonoscopies as they said,

"The patients in Al-Rantisi department, didn't have their right to have the required diagnostic tests in the same hospital they are admitted in, they are sent to another hospitals because of the shortage and absence of needed diagnostic facilities in a hospital considered main in the management of cancer"

Where a surgeon added, "MRI does not present in a number related to the number of population, when they shut off, then we started to refer the patients out of Gaza"

"We haven't enough number of colonoscopies as we should have at least 6 colonoscopies in each endoscopy unit, (therapeutic and diagnostic)" "Colonoscopies spread sporadically and not along all Gaza Strip"

"PET scan isn't present in Gaza"

## - Diagnostic facilities maintenance:

The maintenance of medical equipment is essential to ensure that it functions correctly, efficiently, and lastly to ensure proper clinical management of the patient. Therefore, it is important to set adequate standards for maintenance of diagnostic facilities and to ensure that it is achieved properly. Yet, in some countries, more than 60% of the diagnostic facilities are not used because of lack of facilities for maintenance and repair. It is essential for the operators of equipment and for the hospital maintenance staff to be trained effectively so that the hospital able to keep its equipment in good working state (WHO, 1994). It is appeared from the comments of key informants that the maintenance of diagnostic facilities is very poor where they said, *"If the colonoscopy is not functioning, then it will be not functioning forever"* 

In addition, a surgeon added his comments on a simple test as the leak test of colonoscopy, "All our hospitals aren't good enough and we have poor maintenance of facilities (and this is the half of the problem, as no one knows how is the proper cleaning of colonoscopy done to elongate the life span of the colonoscopy). Even the leak test for the colonoscopies, no one knows how to do it perfectly. We haven't any trained staff on how to care with the colonoscopy"

A radiologist commented, "One of the main reasons for the failure of the diagnostic service is to have a defect or disruption in them. There is no systematic maintenance or devices repair in the Ministry of Health. The idea found in the MOH is about the companies, which bear the subject of maintenance if the disruptions happened during the warranty period. However, after the end of the warranty period, the disruption in the diagnostic facilities will be continued until we brought the necessary pieces to repair from outside of Gaza from the main manufacturer. Thus, the diagnostic service can be stopped for months. If, for example, the disruption happened in the CT then the patient will be pushed to the private sector. This is a big tragedy for the patients ( $(u^{j}u)^{j}$ )". And he added, "The Gamma Camera and the Linear accelerator were present at Prince Naïf

center but unfortunately did not work for a long time due to unavailability of some equipment"

Moreover, he tried to offer a solution for the problem of maintenance that the diagnostic facilities face and he said, "It is necessary to purchase annual maintenance service systemically. Where the annual maintenance service for the CT device for example is estimated of about 50000 dollars. We tried to speak to the ministry for several times, but no one heard us because the devices are increased in number and are more advanced so the repair costs will be high that MOH cannot bear. We are having action only (I = I + I + I) when the equipment is disrupted and it'll cost more than the maintenance costs for sorrow"

Some patients in the focus groups raised the maintenance problem, and they express their dissatisfaction about the problem where they said,

"I want to know why the CT is worked for a week then is stopped because of disruption and they said to us go to Al-Salam center to do CT"

"We were glad that foreign technicians came to the European Gaza hospital to resolve the technical problem in the CT, but one the technicians left the hospital, they said that it's disrupted again, I want a key informant to comment on the issue"

From the key informants and the focus group participants' speech, we can conclude that there is a huge problem in the maintenance of diagnostic facilities and this can affect the quality of the services received by the patients. Where the proper maintenance means higher productivity can mean safer and more reliable equipment, less service cost, less equipment interruption and more returns (Maranga et al., 2012).

## - Diagnostic facilities experts

The problem of the radiologists shortage sound to be international as the figures released by the Royal College of Radiologists (RCR) highlight the increasingly anxious condition in United Kingdom radiology, with the ongoing shortage of radiologists and this had an impact on late hospital diagnoses and delayed scan results (The Royal College of Radiologists, 2017). It's appeared from the speech of the key informants that there is a big shortage of radiologists and colonoscopy specialists in Gaza Strip and this can affect the time of diagnosis as they said,

"We need experts for diagnostic facilities and special for colonoscopy"

"The radiologists that can read the MRI correctly are two to three"

"Our radiologists need more training"

"Ok! We have radiology board program, but we still need more training, more development of what we have, from all the graduates of the radiology board, we have one to two who can read MRI right!"

On the other hand, other key informants exalted on the radiologists quality,

"We have expert radiologists"

"We have radiology board, that graduates a lot of expert radiologists and in each hospital we have three to four graduates from our radiology board"

We conclude from the key informants' speech, that we have deficiency in the radiologists' number that can affect the quality of the received imaging care to the colorectal cancer patients. The radiology board can solve the problem, but it still need more development.

# 4.3 Access to essential medicine

The access to the essential medicines is considered a part from the concept "The right to health". The WHO Essential Medicines List is composed of a set of medicines that "satisfy the priority health care needs of the population". The essential medicines availability can save lives and maintain health. It should be available, affordable, of high quality and to be properly used (WHO, 2000<sup>b</sup>). One of the main global problems is the access to the essential medicines. Where, 30% of the world's population lacks regular access to the essential medicines (WHO, 2004).

The drug prices may differ extremely between countries as some pharmaceutical companies in low-middle income countries burden higher costs than in high income countries, and corruption within the system is common (Cazap et al., 2016).

For Gaza, a lot of external and internal factors affect the access to the essential medicines badly, where in 2014, 47% of the essential medicines are not available. That it could be related to the siege, financial instability, the political division between west bank and Gaza and procurement constraints (Daher, 2015).

The key informants all agree about the accessibility to essential medicines for the oncology patient's problems.

"The availability of medications should be unquestionable"

"It's totally a humanity crisis and conscience crisis"

"The medications availability here is considered a chronic crisis. It becomes a chronic problem without solutions, we try to adapt with"

All key informants agree that the medications and treatment is a right for the patients as some said,

"Every patient has the right to have his medications, and this makes the key informants and the pharmacists to wonder (بخنعهم <sup>اما</sup>م حيرة), if to give all and the medi cations will stop on all or to give to some and to finish with them to see results and not to lose resources"

A key informant talked about the problem they face when there is a shortage of medications as he said,

"The hardest experience ever is to choose someone to have medications and not the other one, as for example we should choose only 10 patients from 70 patients as the chemotherapy vials supplies only 10 patients. As you don't want to give all the 70 patients only one dose from the 17 decided doses, and then to stop for unknown period of time waiting the next dose to all patients, then you'll lose resources without any effect"

"The criteria we use to choose the patients when we have shortage crisis, first politically prohibited, second young age patients and last the good prognosis patients, the rest patients will be referred"

A key informant added, "From our experience, our medications situation told us it's better to avoid getting disease" In addition he added, "The big problem is the interruption of chemotherapy treatment cycle, because the absence of medications, without any knowledge when it will be available again".

The head department in El-Rantisi hospital pharmacy said, "I can't complete with any patient his chemotherapy protocol I've already started, as the interruption we have in chemotherapy drugs inhibit us from seeing the results"

"The patient is lost between on and off cycles of chemotherapy"

"We should lock the whole treatment for every patient to prevent such interruptions, and this need a strategy from MOH, to know the treatment of every patient since the start".

Moreover, he commented on a previous shortage disaster occurred previously as he said, "In the previous September, we reached that all the chemotherapy protocols for colorectal cancer can't be established; as there was no Xelox, Folfox and Folfiri. I appealed on the Facebook and the MOH performed an emergent conference. The problem is solved within one month, but the solutions were transient"

"All the solutions are patching solutions (حلول ترقيعية), we have no permanent solutions, we need a proper flow of medications"

"The best year for the availability of essential medications was 2016, the worst was since April 2017 till now, in the last September 80% of the list were absent, we have no suitability of medications"

"For sorrow we can't have medications stock for the oncology services, as we have shortage in the supply. Since 2017, the supply had been only enough for 2-3 months and always we are in shortage"

A key informant talked about their personal efforts to resolve such a problem as he said,

"We are as pharmacists in Al-Rantisi pharmacy don't depend on the MOH very much; as we try contact with any international visitors to oncology departments to find solutions to the shortage of medications crisis"

Where a key informant said, "*It's totally corruption*" and he accuse the oncologists in patient selection for treatment as he said,

"The corruption takes place in the selection of patients in the case of shortage of medications, as some doctors choose patients to complete their medications course in favor to other patients"

The key informants try to put some solutions for the essential medications availability as they said,

"We need to add the concept of long-term medication stock to the adult oncology services, we need a constant supply of medications, as if we face any shortage in the essential medications, we can open the stock to overcome this shortage. And during this period the MOH can order the medications we need, then we will not face any shortage"

"It's supposed by the government is to know what is the treatment as all for each patient, to be available from the start, to prevent any break in the treatment cycle till the end, and then we said it's done, as if there will be any break during the treatment cycle then the cancer will return aggressive. We should have a contingency plan"

The head department of the pharmacy in Al-Rantisi hospital talked about a bright solution in the current future as he said, "*The pharmacy which is established by PCRF in Al-Rantisi hospital were agreed to serve the adult oncology services beside the children oncology services. This is the luck of adults to receive their treatment in the best quality regarding the safety and absence of contamination, as those helpless patients have low immunity*"

"The most difficult moment, when a patient comes to ask you about his medications and you said there is no medications and you can't answer anything related to the timing of medications arrival!. We are wasting our time and energy in hearing questions without having the ability to answer them"

"We hope that in the near future; the cancer patient receive the care he deserve it, as a lot of patients affected from the shortage of medications"

The shortage of essential medicines for cancer patients is evident and it is officially considered a chronic problem that needs urgent solutions that affect the quality of care received by cancer patients prominently. The provision of the essential medications to cancer patients especially the chemotherapy medications, is a major challenge in the management of cancer patients for the low resources countries (Rodriguez-Galindo et al., 2013)

#### 4.4. Health information system

Reliable information is the basis of decision-making across all health system building blocks, and is essential to identify problems and needs, make evidence-based decisions, help in health research and allocate resources effectively. A good health information system means that all the relevant partners have access to reliable, authoritative, useable, understandable, comparative data (WHO, 2008<sup>b</sup>).

Obviously, all the key informants agreed that we have a poor health information system with major gaps, which it will lead finally to difficulties in giving a proper care to colorectal cancer patient and underperformance, which could be reflected on the outcome of the care received by such patients.

A non-governmental director talked with angry voice about the current health information system, "We don't have clear system, and everyone who contribute in cancer management focus on his personal concern((يغني على ليلاه)). There is no gathering or networking between health providers in governmental, non-governmental and private sectors, then the story will be turned to business and the poor patient will lost in this vicious circle". And added, "Since three years, I call several international organizations to establish a unified electronic system (كن لا يوجد أذان صاغية) without respond"

A senior oncologist added, "Cancer registry is the only component for gathering information about cancer".

Some key informants explained, "As we don't have a clear system then we can't judge the quality of care we have". In addition, they clarified, "With our current information system, we don't know the journey of a colorectal cancer patient or cancer patients in general, majority of the details are lost".

## 4.4.1 Research

Research is effectively integrated with cancer care. Patients with cancer are ideally diagnosed and treated in a setting of multi-disciplinary care and clinical research. This

helps the delivery of the latest, most advanced cancer care to patients in their communities, producing significant health benefits to individuals and economic benefits to the country (Findlay, 2009).

In Gaza, most of the key informants agreed on the absence of research activities, as many of them said, "*The research is absent, only there could be some thesis through the school of public health*" and some added, "*The research is totally absent, with no foundation for it*". Others explained, "*The research activity meaning in Gaza, sporadic activates from master students*".

Some of the key informants attributed the weakness of research activities to the absence of cancer centers in our country, as they explained, "No cancer centers present so cancer research departments are absent". In addition, some added, "The research methodology is not known by majority of physicians, so we need to enforce research culture in our hospitals". Moreover, some of them clarified, "There is no part of finance related to research activities or training courses related to research methodology".

"There are no any motivating factors to do research"

Some of the key informants said that, "We need more researches related to the colorectal risk factors and the causes of the uncontrolled abrupt in the number of newly diagnosed colorectal cases"

From the collected data, a marked weakness and gaps appeared in the research activities in Gaza, it mainly related to absence of knowledge in research methodology and the absence of motivating factors or plans to stimulate the research in Gaza. It is limited to sporadic efforts mainly restricted to master thesis programs.

# 4.4.2 Cancer registry

The cancer registries can directly improve patient care by involving the clinicians all along the research continuum from the definition of the priorities to the proposition of actions as to improve the quality of care (Bouchardy et al., 2014). However, we found that cancer registries were reported to be available in only 73% of 167 WHO member states; ranging from 53% in AFR to 92% in EUR (Alwan, 2001).

Some of the key informants mentioned the cancer registry when they talked about the health information system, without understanding of the sort of data that the registry issued. All the key informants described that cancer registry faced many problems that limit the quality of data produced by. A key informant issued, "*The existing system lacks quick and easy access to the information*". Other clarified, "*We have currently developed our system, by adding some computers to departments and we are hoping doctors would apply this system and be compliance with this system*".

Other key informants talked about the obstacles and problems that the registry faced as they said,

"The main obstacle we have is the coordination between hospitals providing cancer services; the other obstacle is the low number of the staff working in the cancer registry".

"The system is still growing, but still not all patients included, still there's doubling in registration and the system needs to be readjusted"

"For data gathering in cancer registry, it is mainly active surveillance and depends on our workers efforts"

"We don't have epidemiologists, researches and specialized statisticians, which could lead to underperformance and inaccurate data"

"We face many cases classified as colorectal cancer, but when we reviewed the medical file, we found it another form of cancer or not related to cancer at all"

A key informant added about what he wanted from the cancer registry as he said,

"It's supposed by me as a doctor, when I heard about cancer registry, then I'll be able to find all the cancer related news, when I open on their pages, but unfortunately no"

Some of the private physicians do not know about the existence of cancer registry in Gaza, and do not know the kind of data they produce. Moreover, they attributed this to the weak activities of such registry and to the absence of networking between governmental and non-governmental hospitals.

No one can deny the important and vital role of cancer registry in cancer information system in general, but all agreed that the cancer registry face a lot of problems and gaps, that can lead to underperformance or inaccurate data. The underperformance of cancer registry could be related to the poor coordination between hospitals, the shortage in the qualified staff, and incompleteness of the medical files.

### 4.4.3 Medical files

The medical record is a principal part of information system and a main method to maintain all the data produced during the time of hospitalization in the hospitals. The medical record should have principal characteristics that should include history, background, physical examination, diagnostic plan (laboratory and image procedures), treatment plan description and planning for the activities during the hospitalization period. The medical record is good evidence about the healthcare given to the patient during the hospitalization and is the foundation for medical research and health information system and for legal evaluation where malpractice is suspected (Leiva et al., 2012).

Despite this importance, medical record care is often given a low importance. Notes are often poorly maintained and sometimes patient's notes are not readily available (Pullen & Louden, 2006). It is common to find obscured records and missing information, and there is often contradiction between entries by doctors, nurses (Abelrahman & Abdelmageed, 2014).

After evaluating the completeness of 100 medical files in the main hospitals providing colorectal cancer management using the checklist in Annex (3), it appeared that there are many major defects in the completeness of medical records.

### - Demographic domain:

Documentation of patient demographic data is essential. A medical record is considered complete if it contains sufficient information to identify the patient. The lowest completeness of demographic variables domain, as patient ID number, patient age, patient address, patient home telephone and patient marital status where is considered a low completeness as 0% of files have the data mentioned before. For the patient date of birth, only 3% of medical files have patient date of birth recorded in more than the two thirds of the number of pages of medical file. These are considered weak point for the medical files

as shown in the table below (4.5). When comparing our findings with a study was done in the oncology departments of Gaza governorates to evaluate the medical files completeness of oncology patients as general, we found that the patient identification domain completeness is 96.6% (Abu Amer, 2012),. Which nearly about the same which what we had, as 99% of the medical files had patient name.

		Type of filling					
Item	Complete		Partial		Inco	mplete	Total
	Ν	%	N	%	N	%	No
Patient name	99	99%	1	1%	0	0%	100
Patient ID	0	0%	37	37%	63	63%	100
Patient age	0	0%	24	24%	76	76%	100
Patient DOB	3	3%	49	49%	48	48%	100
Patient gender	17	17%	62	62%	21	21%	100
Patient address	0	0%	16	16%	84	84%	100
Home telephone	0	0%	1	1%	99	99%	100
Marital status	0	0%	0	0%	100	100%	100

 Table 4.5 Percentage of completeness of demographic characteristics in the medical

 files in the oncology services in Gaza Governorates

In 2001 a study done in the Adult Cardiology Clinic at Nork Marash Medical Centre to evaluate the patient specific information, the lowest completeness in the structureencountered form was identified for resident name, as it was rarely recorded in the first visit (oksuzyan et al., 2003). Where in 2015 medical records in family health center in El Shorouk City, personal data was filled in 86.5% of the reviewed files (Anwar et al., 2016).

### - Medical record domain

When talking about the medical record characteristics, some variables should be presented and are important to be evaluated as demonstrated by table (4.6).

For the 100 medical files, 25% are with consultation request for variable departments in the hospitals and the rest with no any consultations. The clearance of the consultation report is an important factor to be evaluated in the medical files. As 4% of the files are with no clear consultation, 4% are partially clear and 92% of the files are with clear

consultation report, which is a strong power for the staff to understand conclusions about the case, what should be done, and timing of next follow up. In addition, it appeared from the table below that the author's signature only presented completely in 29% of the medical files, partially in 60% of the medical files and in 11% of the medical files presented as incomplete. The researcher could demonstrate that physicians did not usually add their signatures due to the limited number of human resources in the departments; they know the signature and handwriting of each other as the researcher observed through collecting data. In 91% of the medical records, dates are recorded completely.

When comparing it with the medical records in the family health center in El Shorouk City reviewed (81.5%) of records were signed, (85.5%) of records showed the date of visit (Anwar et al., 2016).

	Type of filling						
Item	Cor	nplete	Pa	rtial	Incomplete		Total
	N	%	N	%	N	%	No
Electronic MR	0	0%	0	0%	100	100%	100
Chief complaint	76	76%	11	11%	13	13%	100
Professional Diagnosis	7	7%	5	5%	88	88%	100
Diagnosis plan	76	76%	7	7%	17	17%	100
Discharge summaries	89	89%	1	1%	10	10%	100
Author identification	29	29%	60	60%	11	11%	100
Dated entry	91	91%	9	9%	0	0%	100

 
 Table 4.6 completeness medical record domain for the medical files in the oncology services in Gaza Governorates

### - Patient history and examination domain

Documentation of medical, surgical, family and psychosocial patient history is important to gather more information about the patient and when accompanied with the appropriate general and system oriented physical examination, it will yield a pathway for the appropriate diagnostic plan to reach to professional diagnosis and finally to the definite diagnosis. It appears that there are defects in family and psychosocial history as 0% of files with complete history, about physical examination only 47% of the medical files with complete general and system specific examination as shown in table (4.7). The researcher may explain this result because of the limited human resources, workload and limited time of the physician to give time to hear and write the history of the patient, which could be the key for the diagnosis of the problem. Abu Amer (2012) found that only 40% of the cancer patients' medical files had medical history which is nearly the same with what we had as only 35% of the colorectal patients' medical files had medical history.

When comparing the result with the result found after reviewing the medical records in the family health center in El Shorouk City general examination is recorded only in (51.5%) of records. Around 96% of records mentioned the past history, out of those with previous hospitalization and previous operations (91.5 %) were filled in all reviewed records. In addition, trauma and injuries filling was recorded in (96%) of the medical records (Anwar et al., 2016).

	Type of filling						
Item	Complete		Partial		Inco	mplete	Total
	Ν	%	N	%	N	%	No
Family history	0	0%	0	0%	100	100%	100
Psychosocial history	0	0%	0	0%	100	100%	100
Medical history	35	35%	21	21%	44	44%	100
Surgical history	35	35%	17	17%	48	48%	100
Physical exam	47	47%	26	26%	27	27%	100

 Table 4. 7 completeness of history and physical examination domain in the oncology services in Gaza Governorates

## - Colorectal cancer characteristics domain

When talking about colorectal cancer, it is amenable to talk about the morphology, behavior (aggressive, metastasis), grade and stage of the colorectal cancer. After reviewing the medical files, 86% of the medical files do not show the morphology (histology) of the

colorectal cancer, 87% of the medical files do not talk about the aggressiveness and metastasis of the cancer, and 97% of the medical files do not provide any information about the grading system. In addition, 96% of the files do not show a clear staging system as shown in table (4.8) below.

This is considered a weak point for the medical files in oncology providing services department as shown in the table (4.8) below. The researcher may explain this because the physicians lack time, heavy workloads and inadequate number of physicians and their relying on the histology report should be included in every file ignoring the possibility of losing such report.

		Type of filling					
Item	Com	plete	Pa	artial	Inco	mplete	Total
nem	Ν	%	N	%	N	%	No
Cancer morphology	11	11%	5	5%	84	84%	100
Cancer behavior	13	13%	0	0%	87	87%	100
Cancer grade	2	2%	1	1%	97	97%	100
Cancer stage	3	3%	1	1%	96	96%	100

Table 4. 8 completeness of cancer related factors in the oncology services in Gaza

# - Medication record domain

When the researcher checked the completeness of medication related variables, it is found that 0% of the medical files talk about allergies the patient could have, 0% of the medication record shown the side effects of the medication, and 70% of the medical files with complete medication records (dosage and date of medications) as shown in the table (4.9) below.

	Type of filling						
Item	Complete		Partial		Incomplete		Total
	N	%	N	%	N	%	No
Allergies and adverse reaction	0	0%	1	1%	99	99%	100
Medication record	70	70%	26	26%	4	4%	100
Medication side effects	0	0%	0	0%	100	100%	100
Plan of treatment	75	75%	18	18%	7	7%	100

# Table 4.9 completeness of medication record in the oncology services in Gaza.

# - Chemotherapy record characteristics

There are 59 colorectal cancer patients took chemotherapy so the chemotherapy request report is essential to be examined, it should have some important items that should be completely filled in order to calculate the chemotherapy dose correctly as body weight, height and body surface area of the cancer patient. It is found that some of the amenable variables in the chemotherapy request form, missed from the medical files as shown in the table (4.10) below.

It considered a strong point in the medical files, where 95% of the chemotherapy requests contain a clear diagnosis, 71% of them contain a clear weight and height, 78% of them contain a clear body surface area, 88% have a full regimen table and 88% of the chemotherapy request have a clear author's identification.

	Type of filling						
Item	Complete		Partial		Incomplete		Total
nem	Ν	%	N	%	N	%	No
Clear diagnosis	95	95%	0	0%	5	5%	59
Clear weight and height	71	71%	0	0%	29	29%	59
Clear body surface area	78	78%	0	0%	22	22%	59
Chemotherapy regimen table	88	88%	2	2%	10	10%	59
Clear author's identification	88	88%	0	0%	12	12%	59

Table 4.10 completeness of chemotherapy request form in the oncology services inGaza Governorate

## - Overall medical record status

When comparing the score of completeness percentage of the medical file main domains between the three main hospitals providing the colorectal cancer services, the percentages are nearly the same between the three main hospitals as when looking to the demographic domain and medication record domain in all hospitals ranges from 32% for Al-Shifa hospital to 36% for European Gaza Hospital. This is considered a weak point for the medical files. Also when comparing the other domains, as medical record domain, history and physical examination domain, colorectal cancer domain and chemotherapy request characteristics domain, all have approximate percentages between the three main hospitals, which reflects that the main hospitals providing colorectal cancer care have the same quality of care provided for colorectal cancer patients as shown in the table (4.11) below.

Hospital	Demographic domain	Medical record domain	History and physical exam domain	Medication record domain	CRC characteristics domain	Chemotherapy record domain
Shifa hospital	32%	63%	40%	59%	7%	-
Rantisi hospital	32%	62%	36%	64%	5%	80%
European hospital	36%	47%	15%	47%	12%	88%
Total	33%	58%	29%	54%	8%	84%

 Table 4. 11 Score of completeness of medical files in the oncology services in Gaza

 Governorates

The obtained results from both the quantitative and qualitative data may allow us to conclude that the medical records of colorectal cancer patients have some incompleteness in many items.

The majority of the key informants attributed the incompleteness of the medical files to either; workload, weak habits from the staff to document the data, deficiency of junior physicians, movement of the patients from a service to another holding their files without networking of the files and the absence of electronic medical files. They all agreed that a lot of patients and medical files dropped out of the system. As a consultant oncologist said, *"Some of oncology patients diagnosed went to Al-Shifa Hospital for the surgical intervention and then he didn't return to us, and the surgical department didn't give us the feedback, then we lost the patient and he dropped out"* and he clarified, *"Completeness of the files is not a culture"*. In addition, when asked about the incompleteness of many items he said, *"It's not the mission of the consultants; this is resulted from the absence of junior doctors"*.

A consultant surgeon added, "We have a huge problem in the compliance of medical file completeness". Another surgeon said, "We need to network the data and management steps done for the patients, this can be done only when turning the paper files to electronic files".

"The doctor due to the load of work has no time to take care of the new cases and complete their files".

A key informant blamed the patients for the losing of medical files data as he said,

"Patients could be the responsible on losing some of the contents of their files such as lab tests and radiologic exams, as they take it to another doctor to see in the private clinics, or when they take it with them during their travel to radiotherapy treatment. Then we found it incomplete".

"The problem in our medical files, that we couldn't know the total story of the oncology patient, we don't know if he is referred or not, if he is died or not, we don't know if he take chemotherapy or radiotherapy, we have a big loss of information, we are poor in information system"

"No complete treatment journey for any patient in our medical files"

Some of the key informants offered some solutions for completing the medical files as they said,

"If every doctor tries to complete his patient file, right this can take from a time, but I will benefit from this effort on a long term, for the continuity of the story of such patients"

"The supervision of the completeness of the medical files should be started as soon as possible; MOH should offer rewards and punishment principle for the completeness of the medical files"

Despite WHO established the International Classification of Diseases (ICD) to standardize medical records and national efforts to introduce and implement ICD-O3 in the medical files, 34.5% of the medical files in all hospital providing colorectal cancer services missed the ICD-O3 classification as shown in the table (4.12). Where Abu Amer (2012) found that only 3.3% of the medical files reviewed in the hospitals providing oncology services had ICD-10 classification.

In addition, none of the medical files mentioned ICD-O3 classified the type of colorectal cancer by using subclasses of C18.

 Table 4.12 Percentage of missed ICD-O3 in the medical files in hospitals providing CRC services

Hospital name	Missed ICD-O3
Al-Shifa Hospital	35%
El-Rantisi Specialized Hospital	39%
European Gaza hospital	30%
All Hospitals	34.5%

Of the 80 colorectal cancer files which are classified according to ICD-O3 in Al-Shifa hospital, 25% of the files where not for colorectal cancer patients as classified under C18, which refer to colorectal cancer. Of the 55 colorectal cancer files in oncology patient report in European hospital, which are classified according to ICD-O3, 20% of the files were not for colorectal cancer patients.

The key informants support these findings, where a consultant surgeon said, "*The filling of ICD-10 or ICD-03 is the responsibility of any physician anywhere, and if it's written the first time right then it'll be written correct always*"

"The problem is our compliance, after training we will write the codes, after 1 month, we will forget to write them"

"It's totally caused by the work overload"

Where a key informant suggested a solution for the problem and said, "We need training on ICD-03 done continuously"

The data of the medical records is the soul of any information system, as improving the completeness of patient's medical records is a vital step towards improving the quality of healthcare (Tola et al., 2017). It's appeared from the results of both quantitative and qualitative data result that the completeness of the medical records is very law, and this probably because the medical team was not aware about the importance of the medical records completeness and it's crucial role in the treatment quality and following up of the patients.

### 4.5 Health financing system

The Universal healthcare coverage belongs to the category of good health and wellbeing for all, which is the third sustainable development goal that assures on raising the access to quality health services for all individuals of all ages around the world, preventing them from financial catastrophes and impoverishing health care costs (Millennium Institute, 2018).

The Ministry of Health should have the role of provision of social health insurance in order to protect the poor and vulnerable from the catastrophic expenditure, which may further push them into poverty (Mwaambi, 2017).

All the key informants reported that MOH suffers from financing instability, and this will prevent the MOH from providing a clear, fixed financial part to oncological services.

"Financing instability resulted because of the geographical division".

"The budget of MOH is totally dependent on the supporting countries, and this budget is only for emergency services, where the oncology is not considered an emergency service".

"Ranging from 18.000.000-20.000.000\$ is the cost of oncological drugs yearly in Gaza Strip"

"The problem that we don't have a fixed funding for the oncological services, the budget is totally allocated from MOH in Ramallah, so there is no continuity in treatment"

"The oncology patient in general doesn't pay anything after the diagnosis; he is totally exempt from MOH"

"We are a poor society and the financing of the Ministry of Health is not stable. Moreover, we have expensive medicines. The situation of patients is very deplorable"

A key informant talked positively about the financing as he said,

"Only governments can bear the cost of oncological services, individuals can't bear the expensive cost of the oncological services"

"The government is thankful that it provides free oncology treatments. This is an advantage that cannot be denied by anyone"

In addition, the participants added their comments on the financing of oncology departments and show their dissatisfaction as they relate the absence of some services related to inappropriate financing of MOH as they said,

"The simplest thing that any patient need during the admission is the food, where the MOH did not send food to the admitted patients any more, which is a disaster; some patients don't have money to buy food"

"Some laboratory tests can't be done in hospitals, where we should pay a lot to do such tests outside the hospitals"

"Every admission, you should bring with you some needed requirements as a pillow, a blanket, a towel, tissue papers, soap; MOH can't supply this simple requirements to every patient, where these simple requirements any outside MOH can provide"

From the collected data, we can conclude that the financial issues for the oncology department are complex and cannot be clear, where the budget of MOH is changing from time to time and cannot specify a fixed budget to the oncology departments.

# 4.6 Governance and leadership

Leadership and governance of health systems, also called stewardship, has been described as the most complex but critical building block of any health system (WHO, 2006). Effective leadership and governance are an indispensable requirement for improved performance of the health systems and development of human resources in low to middleincome countries (Uneke et al., 2012).

All the key informants agree about the limited role of the government in supporting the oncological services, through neglecting the human resources development, reinforcement of infrastructures (building and diagnostic facilities), development of information system and the stability of financing system.

"The oncology departments are huge burden on the MOH, the MOH want to get rid from the burdens of such department" "In Gaza Strip there is no MOH, no one can take a vital decision regarding oncology services"

"MOH neglect the oncology departments totally"

"MOH dealing with the oncological patient as any patient with no specialty"

A private key informant talked with angry voice as he said, "No one hearing to our suggestions". And she added, "MOH killed us (الوزارة هلكتنا ي ولاد الحلال)"

An oncologist added, "They don't care about the oncology departments"

From the collected data, we can conclude that MOH doesn't give a special care to the oncology departments in Gaza, where are a lot of weaknesses and gaps affect the oncology departments and a lot of key informants try to improve the situation by their recommendations but they feel that they can't be heard from any one.

## 4.7 Patient factors

The management steps can be affected by many factors related to the patient himself. From the participants of the focus groups, we can conclude the main factors that can affect the management of their disease. Patient age, the ability of the patient to take a decision (Decisional control), the patient social status and his/her relationships, the beliefs of the patients, the economic factors and prior knowledge of the disease were of the main factors that affect the management of the focus groups participants.

The age of patient was also considered from the patient factors that can affect, where the participants above 65 years old sought the medical help later than those lower than 65 years old may be because the decisional power.

The patient beliefs could be considered as a determinant for seeking the medical help as most the patients who delayed seeing a professional for their symptoms said,

"My disease an exam ( $\mu$ ) from my god, and the fate finally will be a death, so I preferred to stay away from the hospitals". Where another patient added, "Then where we could go away from death, different reasons to reach to death"

A doctor who had colorectal cancer disease added, "I ignored to do screening colonoscopy despite my brother died from the same disease, which is because my belief that everything happened to us is good and planned from the god (قل لن يصيبنا الإ ما كتب الله لنا)"

Whereas other patients added,

"I trust in Allah, and he care about me more than anyone else even my mom ( ثقتي بالله رينا ) " (أحن عليا من الأم على ابنها

"Allah determines our ages, and the death doesn't need cancer (الاعمار بيد الله)

" (والموت ما بدو سرطان

Spirituality can be an important element in the way patients face chronic illness, suffering, and loss, which should be addressed by the physicians, that be attentive to all suffering patients (Puchalski, 2001).

The ability of the patient to take a decision to start his/her management, which is known as decisional control or power, is considered also of the determinants of the management of their disease. As we saw elderly patients tends to hear to their relatives about their symptoms and others cannot even ask to go to hospital as they said,

"I was depend on my god and my relative doctors (كنت اعتمد على الله ثم على قرابيبي الدكاترة), where for three years, I complained from abdominal cramps to them, where they advised to me some anti-cramping medications. Then my state exacerbated till I can't walk and falling down from the least workload, I called a relative and said that I had myocardial infarction. He said no you did not have any and you are in a good state, he said that he would go with me to the clinic to show me that I didn't have anything; unfortunately my hemoglobin level was 5 and I referred to hospital"

Another patient added, "After two months my wife went to take the result of the histopathology report; my sons knew the result just after three days from taking the biopsy, but they saw that I can't bear the chemotherapy and as you see the surgeons operated me too late; they found putrefactions all over the abdomen"

"I'm an elderly, my sons and daughters don't her from me; I had fresh blood in my stool before 6 years for more than 6 months, when I complained they said it's just a hemorrhoid or fissure"

Another patient added his comment with sorrow, "My neighbor advised me to take Augmentin for my abdominal bloating, I repeat it more and more, and now it's too late"

"My relative is a GP doctor, he said to me it's just irritable bowel syndrome, but my symptoms didn't relieved for more than 2 years"

"We supposed that my abdominal pain resulted from the renal colic, I waited and drank a lot of boiled herbs, but no response"

The findings from the participants was in parallel with what is found in literatures, where older adults express a need for shared decision-making (Elkin et al., 2007, Gaston & Mitchell, 2005)

The patient social status and his/her relationships can affect all the management steps obviously, where we found that the patients who has a relative doctor who work in the same hospital where he received his treatment has the advantage on other patients in receiving their management. As some patients said with angry voices,

"We are poor, other patients know the doctor, they don't even wait"

"(الواسطة) and relations (فيتامين واو) "It's all because vitamin "w" (الواسطة)

"Some patient waved their hands to the doctor from the door, then the doctor permitted their entrance, even if I didn't finish my consultation, this is shame (مهزلة)"

Another patient talked angrily as he said, "Why did the patient who came at 1.00 pm enter the doctor room and leave in the same time, while I came at 7.00 am waited after the one who entered at 1.00 Pm"

"Why aren't we treated the same?"

Other patients where advantaged from their relationships as a patient said,

"I had not enter what is called the inpatient clinic since I was diagnosed, my brother is a known doctor; he finished all the needed while my waiting in the day care chairs"

"The colonoscopy was done for me in the next day of colonoscopy as I'm a known doctor, everything I want can be done"

"The colonoscopy was damaged in Al-Aqsa hospital, my relative doctor scheduled me a colonoscopy appointment in the European hospital within two days after"

The economic factor was of the main patient factors that can affect the management according the patient comments. Where the participants in the focus group were of variable economic statuses, as some of them start their management from the diagnosis step in the private sector and have a rapid diagnosis; where they can start their treatment soon after the diagnosis as an average time needed was 2 weeks. There was exclusion for one patient who went to non-specialized doctor in the NGOs and there was a delay in diagnosis of about 3 months. Whereas the other group of patients who start their management later than the first group are with an average of 1-2 months, because they have not the financial resources to seek medical help in the private sector and they either went to primary clinic or to governmental hospitals.

"I did not seek the medical help for more than two years; despite I knew in my deep that I had cancer; as I didn't have money to pay the cost of services"

Other patient added, "In Al-Aqsa hospital, they requested colonoscopy, but the colonoscopy there was damaged, so I couldn't do colonoscopy, and waiting the relieve (أولاد العلال), till some bodies (أولاد العلال) give me the cost of the colonoscopy service and I went to do it"

Other patient answered our question with sad tone as he said, "To where did you want me to go? I went to the near UNRWA clinic, where Dr. XX treated me as irritable bowel syndrome, I returned to my follow-up appointment with no improvement, where she advised me a colonoscopy and referred me to Al-Aqsa hospital, but I did not go till my symptoms exacerbated"

"I went to Abu Yousef Al-Najjar hospital, where I complained of gastric abdominal pain, I made some laboratory tests, where Dr. XX said that it could be an infection, he described for me antibiotics and after a week I returned to hospital with no improvement, I was prescribed medications for more than two months with no improvement. Then I went to a private Dr.; where he thought about cancer and ordered a CT, and he instruct me to do it in Al-Salam center for rapid result and I did it there". Moreover, he added, "the result of CT was not normal, so he ordered a colonoscopy for me and I did it in a private clinic for rapid result and they found a big colonic mass".

Another patient was the different where he went to NGO association, where the diagnosis was wrong as he said, "I complained from severe abdominal pain and continuous vomiting, where I went to Dr. XX in the patient's friend society and he concluded that I had either a lipoma or an abscess that occlude the colon. He prescribed for me medications for 3 months, with no improvement. Then I went to Al-Shifa hospital when the symptoms were exacerbated, and they diagnosed me within 3 weeks as a colon cancer"

Other patients added their comments as they do not went to the governmental hospitals because of delay and their good economic status helped them, "*I did not go to the governmental hospitals, because of the delay; I lost some money in the private sector but I had the result of diagnosis rapidly within two weeks*"

"Fortunately my economic status is good, as my CT appointment was after two weeks, I went to do it in Al-Salam center"

"I did the biopsy in the private sector and the histopathology result appeared within three days, if I want to did it in the governmental hospitals then the result will appear within month"

The effect of economic status on the taking of management decision, which is parallel with what is found internationally; the economic status was found to be associated with health-care delay, late presentation and treatment modalities of patients (Wang et al., 2015 & Ma et al., 2012).

The other factor that could affect the management steps, which was the prior knowledge about the disease, all the participants except two of them did not hear about the disease, which made them not to think about the possibility of colorectal cancer. The other two, one of them heard about the disease in general; its name only so he could not link his symptoms to the disease. The other patient was a doctor and he knew everything about the disease, but he ignored to do screening colonoscopy despite his brother died from the same disease, which is because his belief that everything happened to us is good and planned from the god (قل لن يصيبنا الإ ما كتب الله لنا)

The researcher suggests to do further quantitative study regarding this issue (the patient factors affecting the access to health care) and to include a large sample to quantify the problem, and to estimate the magnitude of the problem and to correct the problem.

### 4.8. Evaluation of the quality of care

When the patient has a disease like cancer, it becomes even more important. A cancer patient not only suffers from the disease itself but also undergoes substantial agony and stress (Mahapatra et al., 2016).

From the collected data, it appears that a lot of gaps & weaknesses emerge from colorectal cancer management. It is difficult to judge on the quality of colorectal cancer management in Gaza Strip by clear results that it depends on the level of management (prevention, screening, treatment& follow-up). In general, many of the key informants judged about the quality of care in Gaza to be acceptable as they said,

"We have very good services provided to oncological patients, where the patient diagnosed and we deal with them in a fast time".

"In Gaza the care is better than in the neighbor countries".

"The quality of care will be more than excellent if all the required tools are available".

"As a surgeon, we can do all the surgery needed for the colorectal cancer patient"

While many of the key informants found that the quality of care is acceptable, other were disappointed about the poor quality of cancer management in Gaza saying:

"It depends, where the patient had his treatment, as not all the places have the same level of treatment quality (where it depends on hospitals and the facilities of the hospitals) where not all the hospitals in the same level. For the governmental hospitals, the quality is very bad" "We can't talk about the quality, there's no quality management in the oncology departments for sorrow for that we haven't qualified services delivered to the patients".

"We have too much patients, too little oncologists, unsuitable buildings, and then the quality is low".

"The system is very bad and this is reflected on the quality of treatment".

The researcher may explain the argument between the key informants point of views concerning the colorectal cancer management. As when the key informant described the quality of care, he described it according to the level of care he provided, which he is responsible and it depends on his expectation and his updating; but there is no suspicion about the presence of many weaknesses and gaps in the colorectal cancer management in Gaza.

During exploring the management journey for the colorectal cancer patients, a case was found who was died before two years; her story was told by her family, "Our mother was 63 years when we discovered that she had a late stage colorectal cancer disease. She had three of her sisters died from colorectal cancer, as they are discovered in late stage with metastasis, no one advised our mother or any of my aunts to have any screening test, although our family is full of doctors! If they told us to do such tests, we could save her, even after discovering her disease, no one advised us as her daughters and sons to do any screening test!" In addition, they added, "When she complained from rectal bleeding, we supposed that she had hemorrhoids even that our aunts died from colorectal cancer, she went to a private female doctor after she complained from very painful constipation with bleeding. Her doctor talked with her, had the medical history, and examined her, where she supposed that our mother had grade III of hemorrhoids, and she started to treat her hemorrhoid for more than 3 months with no improvement. We went to another female private surgeon doctor. Where she also said that our mother had hemorrhoids without considering her family history and the high possibility of colorectal cancer disease occurrence, she said that our mother's hemorrhoids should be operated because it was not treated with medical treatment. She did the surgery and she did colonoscopy after the surgery; where we found the disaster; a huge rectal mass about 10 cm, and her doctor told that your mother had this mass since approximately more than 6 years! We did the biopsy and she had adenocarcinoma! Her cancer could be prevented if we knew about the

symptoms of colorectal cancer disease or even discovered in early stage if we did just a screening test or if we went to a qualified doctor who considered her symptoms and her family history or treated effectively, but what could we say, thanks for Allah (الحمدلله)"

As concluded from the key informants and the life history of a colorectal cancer patient, we have defects and gaps in the management of the colorectal cancer disease starting from the prevention and ending in treatment and follow-up.

# 4.8.1 Colorectal cancer management strategies

The national cancer control strategy should cover the primary prevention, early detection, diagnosis and treatment, palliative care, cancer registration and cancer research. The program should be reviewed and contributed by all the stakeholders and supported by the MOH (WHO, 2009). Less than one-half of the 167 WHO states (43%) reported that they have NCD polices and only one third to one-half having cancer control plans (Alwan, 2001).

The Palestinian National Strategy on Cancer Prevention and Control published by MOH (2010), it aims to reduce the level of the major cancer risk factors (tobacco smoking, dietary factors, physical inactivity, overweight and obesity, alcohol use, and exposure to different carcinogens). No one of the key informants working at the MOH in Gaza knew about its components, as it appeared from their responses; when there were asked about any existing plans or policies to control cancer in Gaza.

Of the entire key informants, only four of them working in the governmental hospitals knew and have accessed to the published written strategy for controlling cancer. Moreover, only two of them knew the year of publishing of last cancer control strategy. This result may allow us to conclude the presence of poor communication and involvement between the ministry of health and key informants.

The information obtained from the key informants' interviews may indicate that there was a lack of clear strategy to control cancer as a key informant said:

"As I know there is no specific strategy for cancer management in Gaza"

Another key informant added, "We have only general guidelines, and every doctor apply these guidelines according to his knowledge". Moreover, he added, "We are in the European Gaza hospital has guidelines special for our hospital, different from El-Rantisi Specialized hospital"

A private surgeon added his comment, "To the best of my knowledge, there is no what is called strategy for management of cancer in Palestine"

Where in contrast a governmental surgeon said that we had a strategy but "It's not applicable!"

In addition, the majority of the key informants clarified the problem and the gap to have a unified colorectal cancer management strategy, that we do not have networking of the colorectal cancer management activities between the main health care providers (the governmental, non-governmental and private health care centers and hospitals) as a private key informant said,

"The system we have is a fragmented program, not coordinated and not unified". In addition, he added, "How could we have a national strategy with the fragmented health care system?"

In the other hand, a key informant talked about the reason of not having a strategy as he said, "There is no networking or gathering of work between governmental and non-governmental centers. So sometimes, the story turned into business oriented, and the patient will be lost in the cycle"

"We don't have system. In addition, in the available system we do not have transparency. Then how could we have strategy?"

The results showed that the networking and coordination of management efforts and activities to control colorectal cancer between the variable health providers (governmental, private and the nongovernmental organizations) are absent, which may lead to ineffective and inefficient work in controlling and managing the colorectal cancer disease. Supportive leadership, proper planning, collaboration between the main health providers, education and training and effective management of resources and processes improve the quality of medical services (Mosadeghrad, 2014).

### 4.8.2 Evaluation of colorectal cancer prevention

Despite that WHO highlighted on the importance of prevention of cancer in general, to minimize the premature deaths due to cancer in Eastern Mediterranean Region (WHO, 2011<sup>a</sup>). Of 167 WHO member states, less than one-half of the states (43%) reported that they have NCD polices and only one third to one-half having cancer control plans (Alwan, 2001).

Cancer prevention in Gaza has no distinct shape, but it seems to be very weak& not used. Although the Palestinian MOH emphasized on the importance of enhancing the citizens' health and wellbeing through strengthening preventive health care, raising public awareness and promoting healthy lifestyle (MOH, 2016).

All the key informants agreed on the absence of prevention for the colorectal cancer in Gaza Strip in this area in Gaza saying:

"We are very far from prevention of colorectal cancer"

Another key informant said, "We don't have any prevention program related to any type of cancer, even sporadic programs. And he added, "MOH can't take the responsibility of community based health education"

An oncologist added, "As for health education, we are still very late, because there is no any a very national strategy"

"Our people are unaware about colorectal cancer, no one advise them"

A consultant surgeon put a simple solution as he said, "Prevention of cancer is hard ( الحرب) we should pick up high risk cases early, and when to be discovered is our mission"

A group of key informants talked about health education as they said, "We have great troubles in public awareness and we don't have methodologies to increase people awareness"

"The level of nescience about colorectal cancer in Gaza strip is more than any of the developed countries"

"No one teach our people"

"At least educate the family of the member who has colorectal cancer when to do screening tests"

A key informant talked about the satisfaction of the health providers about the prevention programs as he said, "We are not satisfied about the current prevention activities, as we all ignore the colorectal cancer problem although we are surprised by the elevated number of cases"

"No one can take any action in prevention programs related to colorectal cancer as we haven't clear system"

Another key informants talked about the drawback of health awareness programs as she said, "We discussed the inability to carry out such public awareness campaigns, as if I discovered cases, then where those cases should go, we don't have capacity to bear such overload"

"We don't have what is named as prevention programs, it should be applicable as a package of health education sessions to increase public awareness, FOB at least to be done once yearly, colonoscopy (every 3-5) years"

"There are no prevention programs from either the ministry of health or any form of private institutions or non-governmental institutions. We must have a national vision for prevention program. What is supposed that the ministry is looking for the external budget to start a national colorectal prevention program"

The obtained results from the patient's participants in the focus group concerning the colorectal cancer prevention programs were with the obtained result of key informants. Few of the participants in the focus group clarified that they heard about this disease only its name from some friends and relatives without any information related to the symptoms or the causes.

## 4.8.3 Evaluation of colorectal cancer screening

Colorectal carcinoma is considered a serious public health threat. Detection in its early stages is the best predictor for long-term survival, which is the reason for population-based screening programs (Dobos & Rubesin, 2002).

CRC Screening programs are currently proceeding in most European countries, Canada, specific regions in North and South America, Asia, and Oceania. The most widespread screening strategies were based on fecal occult blood testing, and more recently, the fecal immunochemical test (Navarro et al., 2017).

Most cancers present in advanced stage in developing countries when cure is hard even with best options of treatment. A major element of improved survival rates for many cancers in USA and Europe is brought by health education and screening for some cases (WHO, 2009). It seems that Gaza also is one of the regions of developing countries that having this problem. The absence of colorectal cancer screening program in Gaza is confirmed by what the key informants said,

"We didn't have any screening program for colorectal cancer"

"There is no prevention and no screening available for colorectal cancer".

Another key informant demonstrated that screening programs are not from the policy of MOH as he said, "We have no policy of screening in MOH for Colorectal cancer, we only did diagnostic workup according to the patient symptoms despite the screening tools are feasible"

"I'm not satisfied about screening and prevention programs, we need earlier discovering and treatment of colorectal cancer to prolong the life of patient"

Other key informant talked about the problem from another side, where he related the problem to inadequate and improper infrastructures as he said, "We don't offer screening programs for colorectal cancer because the number of doctors is inadequate, the number of colonoscopies and the number of colonoscopy units are insufficient and this needs a national strategy". Moreover other added, "As medical staff, we don't have full awareness about screening programs of colorectal cancer; we don't know who to send to either FOBt

or colonoscopy". In addition, other key informant added, "The early detection of colorectal cancer is a big problem and it has many requirements. I think it is a governmental strategy and not only a strategy at the ministry of health level. The government should cover the Ministry of Health early detection financially". A key informant talked about simple test for screening with sad voice as he said, "FOBt isn't always available, and if it's available, it's not used and could reach expired date with no using"

A consultant surgeon talked about some sporadic cases as he said, "Screening in Gaza is sporadic and is dependent on the doctor judgment and his brightened conscious ( ضميره) as there is no clear system, where some doctors refer any individual above 50 years for FOBt"

Some of the key informants offered some solutions to start colorectal cancer screening programs,

"We should have screening program for colorectal cancer, to decrease the burden of late diagnosed cases"

A consultant surgeon added, "Our people should be classified according to risk score and this should be enforced by community based health education as screening is a big insult for colorectal cancer management". In addition, he said, "We should have the concept of self-discovering for colorectal cancer, as individuals should have high sense about symptoms they developed (Altered bowel motion or changed stool color) then he should do at least FOBt"

"Because the number of CRC is increased abruptly, then we should activate the screening (for all population if feasible)"

"The private and governmental doctors in any specialty, in any level should advice for screening for every patient or every patient relative they met"

"Screening colonoscopy should be used as a screening tool for each individual above 50 years"

"The endoscopy tools for screening should be available as a free tool for all population as the patient can't afford to pay money for colonoscopy"

"10% of CRC cases are due to familial cause and 90% are sporadic cases, for the familial cases, they have higher risk to develop it so we should approach them to do early screening methods"

*"FOBt should be presented on the spot in each clinic and if we have a positive result then to send them for endoscopy"* 

"Genetic studies should be done for high risky patients, in young age, but not to be overused, only to be done for selective cases"

In the other hand, a key informant highlighted that the problem is not related to the screening program itself, but the steps that should be taken after the screening program as he said,

"Not if we did the colonoscopy once, that's it. There should be follow-up"

"It's supposed for us to have guidelines about what to do next (When to do another colonoscopy if you find a polyp). We should do it every 3-5 years and this depends on the size, site and nature of polyp"

As it appeared from the justifications of the key informants, screening program for colorectal cancer is absent in Gaza. Efforts are needed to organize an effective screening program in the developing countries. These countries should find adequate financial resources, develop the infrastructure, train the needed human resources, and improve surveillance mechanisms for screening, investigating, treating, and following up the targeted people (Sankaranarayanan et al., 2001).

All the participants in the focus group were asked if they heard or did any scheduled screening test or even by chance to exclude colorectal cancer before their final diagnosis the responses of all of them were, "no". Only one participant was an orthopedic specialist where he said, "*I did not do such tests because I did not care despite my brother died from colorectal cancer*". In addition, they are surprised about the presence of such tests for early diagnosis. Moreover, everybody agreed that they did not know about this early detection

tests or did them (in spite that there were at least three of the participants had positive family history for colorectal cancer).

#### 4.8.4 Evaluation of colorectal cancer diagnosis

"The problem of colorectal cancer diagnosis is complex, as if the patient starts to have any complaint related to CRC, he will go to GP, the diagnosis will be late for another 3-4 months. Moreover, if the patient gets tired more, he will go to the governmental hospital, the colonoscopy is asked by his physician, but long waiting lists for colonoscopy will push the patient to private hospitals for colonoscopy. The patient as known don't have the cost for colonoscopy test (500 NIS), as a result he will wait with no treatment and this can magnify the problem more"

The result obtained from the key informant interviews explaining the cause for late colorectal cancer diagnosis that were chiefly linked to the system, health providers and the colorectal cancer patients themselves, which in parallel with what found in literatures (Esteva et al., 2007).

#### - Patient delay:

The majority of the key informants interviewed emphasizes on the negative role of the patient in ignoring his symptoms and late seeking of medical help as they said,

"The late diagnosis of colorectal cancer is chiefly due to law awareness of patients and their families"

"Patients are not aware of their symptoms"

"Our people culture that the final fate of cancer is death, so they neglect their symptoms"

"Some of patients try traditional treatment methods for a long time before seeking medical advice"

"Most of our patients are under the poverty line, so they can't seek the medical help easily"

"Some patients are of high education level and know that they have alarming symptoms, but they afraid to seek medical advice, they afraid from cancer name"

Most of the colorectal cancer patients participated in the focus groups agreed on the concept that they played a role in diagnosing their disease lately,

A participant in the focus group said, "I have been complaining from alternating bowel habits with abdominal discomfort for about three years, but I never seek the medical advice"

Another participant blames his daughter and himself for late diagnosis as he said, "My problem starts before 6 years, when I complaining of bloody diarrhea almost week after week, but my daughters suggest that I have hemorrhoids, so I start to have traditional treatments, with no improvement"

Another patient tried to treat his symptoms by himself as he said, "I treating my symptoms with many courses of Augmentin with great response first"

Another patient blame his poor economic status for late diagnosis as he said, "*I didn't have money to seek medical help at first for 2 years, but when I have money I went to hospital*"

Two patients agreed that the final destiny of any one is death, so why to be urge? As they said,

"The death is resulted from many causes (تعددت الأسباب و الموت واحد), so if they said you have cancer, what will be changed?"

As we conclude from the participants in the focus groups that the patient plays a role in the delayed of cancer diagnosis, which were matched with what found in the literature review, which were mainly related to unawareness of the patients, embarrassment of patients, fearing from a possible cancer diagnosis. A family history of cancer together with a negative attitude to the medical profession can also be a reason for delay. Additional factors may include patient age, civil and social status, mistrust in doctors or lack of time to visit a physician (Hackett et al., 1973; Byles et al., 1992; Sheikh & Ogden, 1998; Dent et al., 1999).

#### - Health provider delay:

The general practitioner plays a dynamic part in cancer diagnosis, contributing in nearly 63% (Ruiz-Torrejón et al., 2006). However, we found that the health care provider played another role in cancer diagnosis delay as both key informants and patients explained.

Large proportion of the key informants said, "The problem is starting before the hospital line, as after the patient ignorance for his symptoms for a long period of time and his symptoms are worse, he went to a GP doctor in the primary care clinics, the doctor gave him medications treating his symptoms for several courses. It's supposed by the MOH to educate the GP doctors about the alarming symptoms"

Most of key informants agree that GP doctors need more training to pick up cases, "We need training courses for the primary health care doctors, as they are the first line dealing with patients". In addition, other added, "We should educate the general physicians how to pick up cases and if the FOBt is positive, then he should refer the cases for colonoscopy and as a result we will decrease the number of cases need colonoscopy"

Another key informant talked about training of general surgeons to pick up cases early, "The quality of surgeons should be raised, as for the hemorrhoids problem in elderly, we should do a colonoscopy before hemorrhoidectomy, but a lot of cases had hemorrhoidectomy, then the main problem will be discovered after a long period of time (بعد فوات الأوان)"

Another key informants blames the poor patient-physician communication as he said, "We are not patience to give the patient his rights, at least to hear from him"

Other key informants blame the experience of health providers for the delay of diagnosis as they said,

"The diagnosis depended on personal bases according the doctor, whatever he is in private sector or inside the governmental hospital; each doctor has his own experience for diagnosis".

"All what we need is a high index of suspicion to pick up cases"

Two patients blame the health care providers for the delay for long period in their diagnosis and said,

"I stand for 1 year between the laboratory and emergency department in Al-Aqsa hospital , my god will take my right from them (حسبي الله و نعم الوكيل عليهم), they told me I had irritable bowel syndrome once, others told me you had crhon's disease, until we went to Al-Salam center to do colonoscopy and they found a large mass"

"For 2 years, I had abdominal discomfort, I went to Nasser hospital and a doctor there told me that you had irritable bowel syndrome, I took medications with no response, till I had blood in my stool"

The health provider could be a key for colorectal cancer diagnosis as seen from the comments of the key informants, where continued training is advised for the physicians to enhance the knowledge about the most vulnerable people for the colorectal cancer to enhance the screening modalities and the early diagnosis of colorectal cancer disease (Siminoff et al., 2015).

## - System delay:

As shown in tables (4.3) and (4.4), our hospitals has a shortage in the diagnostic facilities, which is in parallel with what the majority of the key informants emphasized that health care system in Gaza Strip is the main cause for the delay of colorectal cancer diagnosis as they said,

"We have wrong infrastructures ((ما بني على خطا فهو خطأ), our patient is lost between the governmental, private and non-governmental hospitals and centers"

"The patients in Gaza do not know where to go; they go from a center to a clinic, from a clinic to a center, which take a long period of time. It is supposed to have a major oncology center and to teach alarming symptoms to public. The delay is not the patient's crime, it's the crime of the system we have"

"Overloaded hospitals with long waiting lists and not working instruments, as a result the governmental hospitals will push the individuals to the private sector, and because the

economic status the individuals can't pay . And sometimes if the patient makes his efforts to do the colonoscopy (دبر حاله) then he will object on the cost of Moviprep"

"If possible, the government hospitals should contract with the private hospitals to do colonoscopy, because the patients can't bear the cost of private colonoscopy. When the patient object on the cost of colonoscopy, I offer him the governmental hospitals, he said the hospitals push us to come here (طفشوني), then he asked me to prescribe him any medications that minimize his symptoms"

"We have limited number of diagnostic facilities, limited number of colonoscopies, limited number of pathologists, this is all reflected on the time needed for diagnosis"

Where some of the participants in the focus groups added their comments on the system delay role in the diagnosis as they said,

"I want to know why the CT is worked for a week then is stopped because of disruption and they said to us go to Al-Salam center to do CT"

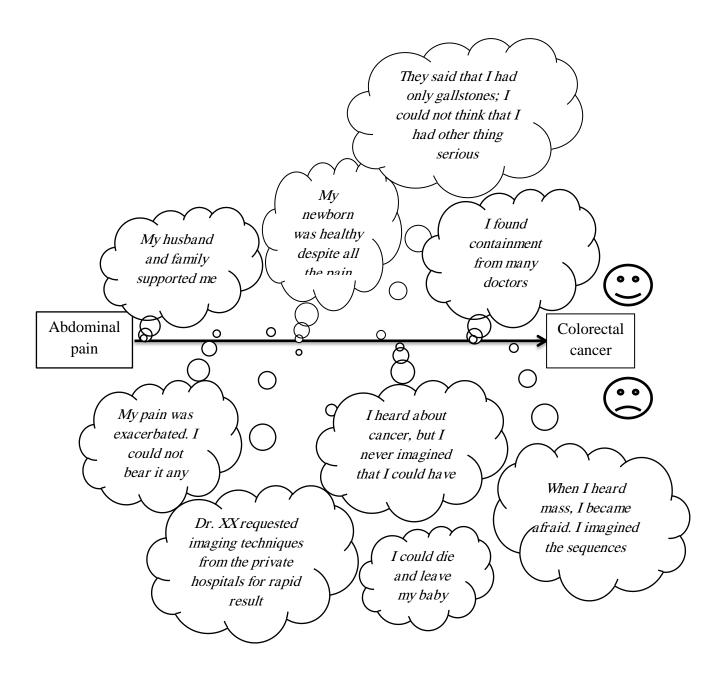
"We were glad that foreign technicians came to the European Gaza hospital to resolve the technical problem in the CT, but one the technicians left the hospital, they said that it's disrupted again, I want a key informant to comment on the issue"

From the collected data from the key informants, it was clear that the health care system in Gaza play an important role in delayed colorectal cancer diagnosis, as weak coordination between services, limited number of diagnostic facilities or limited number of human workforces. Health care system related factors described as possible contributors to delay include specialist referrals' waiting lists, poor coordination, and complementary examinations (Esteva et al., 2007).

During exploring the diagnostic journeys for the colorectal cases in the focus groups, we found a case somewhat different from other patients, as her diagnostic story was;

"While I was pregnant before 6 months ago, I complained from non-routine abdominal pain, I thought that it was the labor pain. Two months after birth, the abdominal pain is exacerbated; where I went to Abu Yusuf Al-Najjar hospital, they prescribed for me only analgesics. Then I went to Al-Shifa hospital, they requested for me U/S and found that I had gallbladder stones. When I was waiting my operation appointment, my abdominal pain was exacerbated. Then I went to the head of the surgical department Dr. XX, where he requested for me CT from Helal-Haider hospital for rapid result as he said, and unfortunately they saw that I had a colon mass, MRI was also requested from Helal-Haidr. Colonoscopy was done in Al-Shifa hospital, and the result was confirmed within 1 and a half week, and I had colon cancer"

When she asked about the good and bad things that happened during her diagnostic surgery, she abbreviated her journey in the following graph:



#### 4.8.5 Evaluation of colorectal cancer treatment

Countries have different abilities for cancer care, depending on resource availability. Lowmiddle income countries usually have insufficient funds for health care, which can be reflected on the mortality rates (Horton & Gauvreau, 2015).

Several approaches to treatment found, including all modalities (surgery, radiation, systemic therapy, or combinations). In the developing countries, access to care may not exist. Most cancer centers in Low-middle income countries use modified treatment regimens derived from those used in high-income countries (Cazap et al., 2016).

#### 4.8.5.1 Surgical treatment

The results gathered from the majority of key informants showed that surgical colorectal cancer treatment in Gaza is considered unsatisfactory and have some gaps. As it still considered as general surgery with no specialization & it needs updating & more training related to laparoscopic colectomy.

A private consultant surgeon said, "All surgeons can do colectomy but we don't know if they do it according to the standards? If they do oncological resection, or only a palliative resection, to say that I did the proper oncological resection, I should remove 12 lymph nodes". A governmental surgeon agreed with the previous talk as he said, "We have no specialized surgeons in our surgical departments". And he clarified his talks, "The oncology specialized surgery is totally different from the general surgery"

Another surgeon said, "This surgeon work as he want (فلان بشتغل على كيفه) and another surgeon work also as he want (فلان برضو بشتغل على كيفه), no one follow-up the quality of surgeries"

A consultant surgeon talked about the international colorectal surgery, "Outside Gaza borders, they started to do laparoscopic resection and this doesn't present in Gaza Strip for sorrow". Other added, "The trend nowadays is toward laparoscopic resection, where here in Gaza only one to two surgeons can do it". Other surgeon added, "Laparoscopic approach in CRC are not performed, done only by foreign visitors"

A surgeon talked about what is needed to have high quality colorectal surgeries and he said, "Our surgeons need training, need someone who follows their surgeries (موتاجين حسيب)"

Other surgeons talked about some surgeries absent from Gaza as they said,

"We can't operate the palliative surgical treatment"

"If the patient has liver metastasis, then will be referred as we can't manage here"

Where other key informants considered that surgical treatment here in Gaza is acceptable as they said,

"There is no delay in the surgical treatment after diagnosis, once the colorectal cancer is diagnosed, the patient receives the surgical treatment, but it depends on the stage of cancer"

"The majority of cancer surgeries that we are doing well and done at proper time"

"We can do 99% of the surgeries needed for the colorectal cancer"

"For the surgical treatment; 85% of cancer patients can undergo the surgical treatment, and the rest can be transferred abroad not because of the lack of experts but because of the lack of the needed equipment for these operations".

From the collected data, we conclude that the surgical treatment related to colorectal cancer needs updating related to laparoscopic colectomy, palliative surgical treatment. In addition, we need specialization of surgeries according to the tumor type.

#### **4.8.5.2** Chemotherapy treatment

Both the key informants and participants in the focus groups informed that the drugs of cancer treatment usually were present as chemotherapy (immunotherapy and hormonal) it was available in the European Gaza and Al-Rantisi Specialized hospitals, but some drugs were not available from time to time. Even some drugs are stopped since months and were not sent again.

A consultant Oncologist said, "Both European Gaza hospital and Al-Rantisi hospital can offer chemotherapy treatment, but not radiotherapy or PET scan"

Where another private key informant talked about the problem of chemotherapy as she said, "*The reason that we didn't have a high survival rate that we hadn't continuous cycles of chemotherapy*"

Another key informant think if we have chemotherapy drugs, what could be happened as he said, "*If the chemotherapy drugs are permanently available, then 75% of the referral cost can be omitted*"

"The used chemotherapy protocol is determined by the medication which presented, because of siege some drugs had not sent since more than 2 months, then the protocol can't be established, we jump between the lines and protocols to coop with the available medications"

"The disaster when you are rejected to cross to west bank and no chemotherapy available in Gaza, then you are waiting the exacerbation of your disease"

Other key informant talked about some sporadic solutions for the problem as he said, "Because the shortage of the chemotherapy, some patients can buy the vials of chemotherapy, as there are some patients can buy till 5000\$, but this is not a solution for the shortage as not all our patients can offer the money". Other added, "Sometimes the patient can offer to buy chemotherapy drugs when there is shortage, as it cheaper than the referral cost". Where other key informant added, "Even if the patient can have enough money to pay the cost of his treatment medication, it is not always found in the private pharmacies, as these pharmacies do not usually bring the cancer treatments medications, and they need an exceptional approval from the ministry of health".

A key informant talked about how the chemotherapy affect the patients, "Sometimes patients suffer from cutting out of their treatment when the drugs are not available and in the same time doctors face the dilemma of changing their treatment or waiting for the drug to be delivered again, which affects badly the treatment prognosis". Where another added, "The on & off cycles of chemotherapy affect the survival of our patients, many patients had metastasis and lost their life waiting the chemotherapy medications arrival"

"Our problem is the sustainability of chemotherapy medications"

Focus groups participants also have their part of complaining concerning the shortages of some drugs, which are necessary for their treatment as one of them, said with an angry tone, "*My medication is not found in the previous September, where they offer for me the referral but I rejected unfortunately*"

"We thank the health care system to offer the medications freely, which is good, but the problem is that I went to the hospital 4 times per month and I did not find the medications"

From the collected data from both the key informants and focus group participants, we found that the ongoing sustainability of drugs represented the main problem especially for the chemotherapy; which can affect the prognosis and the survival of the colorectal cancer patient.

#### 4.8.5.3 Treatment by Radiotherapy

Radiotherapy is a modality commonly used in the treatment of colorectal cancer. For anatomical reasons, however, its applicability is much wider in rectal cancer (Agranovich & Berthelet, 2000). The absence of radiotherapy treatment in Gaza represented an important obstacle in cancer control in general and colorectal cancer in special that was noted by all the key informants as they said,

"The major problem we face in the rectal cancer is that we need radiotherapy treatment before the surgical treatment, which is not available in Gaza. Then the patient will wait the approval from Israel (زحت رحمة اليهود)"

"Radiotherapy treatment and PET scan are unfortunately not present in Gaza, and could not be present in any case"

Some key informants talked about the importance of radiotherapy for rectal cancer as they said, "The rectal cancer patients are very poor, it's supposed for them to start radiotherapy as soon as possible after diagnosis, but they can't start because it isn't available and long waiting list to be referred. So we have delay on the treatment of rectal cancer patients". In addition, "The problem in Anorectal disease treatment, where patients need chemo radiation, where radiation is not present in Gaza"

A radiologist talked about the missed opportunity we had, "The prince Naïf radiology center, is one of the tragedies that Gaza had, which was full of good features; if it worked, where it was prepared with the radiotherapy device and PET scan device, but unfortunately it not worked"

From the patient's point of view and the data collected during the focus groups about the patients suffering due to the absence of radiotherapy locally, they clarified that their travel represented for many of them a financial, emotional and physical burden. Added to that some of them have not been permitted to cross Erez check point where they said,

"I waited for 2 months for the permission to have radiotherapy in Jerusalem, but unfortunately no reply came, and I referred to Egypt, where I saw the death in my eyes (شفت الموت بعينيا على المعبر) and it cost me a lot

"My crossing through Erez check point, to have my radiotherapy courses was very difficult as my approval didn't reach for more than months, my treatment is delayed"

From the collected data from the key informants and focus groups, we can say that radiotherapy has not been available in Gaza. Where the colorectal cancer patients who need the radiotherapy treatment were referred either to the occupied Jerusalem or to Egypt. The delayed initiation of adjuvant chemotherapy, defined as  $\geq 8$  weeks, is associated with lower overall survival in colon cancer patients with stage II or III disease (kim et al., 2017).

The lack of radiotherapy is not special for Gaza only, where the International Atomic Energy Agency (IAEA) has brought to world attention, some 30 developing countries, including 15 in Africa, do not possess even a single radiation therapy machine (WHO, 2010<sup>b</sup>). There are only 84 radiation therapy centers, 256 radiation oncologists and 473 radiation technologists in all Arab countries as example; 4 in Jordan, 2 in Qatar, 2 in Syria, 6 in Lebanon and 6 in Morocco. That it is compared with 1875, 3068 and 5155, respectively, in the USA, which has an equivalent population of about 300 million (El-Saghir et al., 2007).

#### 4.8.5.4 Evaluation of supportive emotional care

Earlier diagnosis and developments in cancer treatment mean increase the number of cancer survivors. The impact of psychological morbidity when living with and beyond a cancer diagnosis is now well recognized and has consequences, not only in terms of quality of life but also in overall healthcare outcomes and costs (National Health Services, 2015).

The psychological support in Gaza is absent, or present in sporadic cases form international organizations, where it is not considered from the strategy of MOH in the management of cancer in general and colorectal cancer in special,

A key informant said, "The psychological support is a failure for MOH, where it is absent totally". Other said, "We have no supportive emotional care, we are in need for institutions, social workers, psychiatrics and specialized nurses"

The head of nurse department added, "We requested a psychological worker since more than eight years from the MOH; I had the letter that we sent, and no reply till this moment!"

A chief oncologist said, "We try from ourselves as oncologists to provide some advices to our cancer patients, but we are not used to deal with such cases especially from psychiatric points of views". In contrast, other key informant said, "Our doctors, surgeons and oncologists deal with the patient routinely, as they are just a medical file, which is a disaster"

All key informants agreed that there should be a rapid solution for the problem and said, "*This issue is critical and need a rapid modification if you need a good quality of care*". Other added, "*Our patients are poor need the psychosocial support as a package with their medical treatment*"

From the data collected from the key informants, we can say that the supportive care in Gaza endured a deficiency. The data also collected from the patients allows us to obtain the same result, for example, what the participants said about the day care unit in the European Gaza hospital,

"The doctors here want only to tell you that you had cancer, they don't know how to deal with me, and the issue is not so easy to tell me that I had cancer!"

"We want them to deal with us with humanity"

"If the doctor knew you, then he can talk with you with humanity, with respect, if not then Allah can restore your needs ( (الله يعوض عليك)"

"Why did not the doctor, the nurse put themselves in my place ( (ليش ما ينزلوا لمستوانا?), Why they talked with me like that?"

"Why did they lose if they talk to us appropriately?"

Where two participants talked angrily about the same nurse in the day care clinic and said,

"Why did the nurse XX shout on me and prevent me from seeing my Dr. XX after finishing my chemotherapy dose?"

"The nurse XX shout on me despite I'm older than his father"

Four participants from the focus groups done in the European Gaza hospital added that they met a volunteer female psychotherapist and said,

"Her advices were useful; we hope that we met her every time we admitted"

However, they added that our religion and spiritual life provide them the relief from all depression and anxiety accompanied with their disease,

'I believe in Allah (ثقتي بالله كبيرة), I can fight cancer, and I'll win ( ثقتي بالله كبيرة), I can fight cancer, and I'll win ( أنا حكسر السرطان مش هو الي)

"I trust in my god, and if someone asked me, what do you want, I'll chose what my god chose for me"

A key informant added,

"Our people's faith is strong and their families understand, and the treatment is usually successful"

"People are generally receptive to have cancer"

On the other hand, in the participants of focus groups they agreed that the supportive care depends on who provide them the care, as they stated

"The majority of doctors and nurses were very kind while others were not"

Some key informants agreed with the focus groups participants that we have limited supportive care provided and was offered sporadically with no clear system. It depended only on the personal characteristics, skills, experiences, and workload and the time of the provider as several of them explained as they said,

"If we give from the time of each patient two minutes asking them about their health, then they will be happy"

"We have no supportive care in our cancer departments, but patients receive it when they come individually, and it depends on the level of the doctor who gives the support"

The supportive care in Gaza possess many gaps, which parallel to what found in literature, as there is a need for therapeutic and educational programs-including counseling for those patients with cancer and their families, support groups, and behavioral therapy (Al Jadili & Thabet, 2017)

#### **4.8.5.5** Evaluation of the palliative care:

Providing optimal palliative care for the patient with advanced colorectal cancer is a complex and challenging process (Dixon & Stamos, 2004).

From the results obtained through the key informants' interviews, the absence of palliative care in Gaza was clear,

A private key informant said, "What is named palliative care is totally absent!" In addition, other said, "Such poor patients, need better medical care"

#### "We haven't what is called pain clinic!"

Other key informant commented on the palliative surgery and said, "Even the surgeries for terminal cases, doesn't present in Gaza, to reduce the suffering of such patients!"

"We are silly (احنا بنضحك ع حالنا) when we said that we have a palliative care!"

"We have only mass production care, with no care for the patient suffering"

From the collected data from the key informants, we can conclude that the palliative care in Gaza is totally absent also palliative surgery and pain clinics were absent.

In addition, a key informant talked about deficiency of experts in palliative care as he said,

"We have no physician who is expert in palliative care or even nurses specialized in palliative care"

The shortage of palliative care in Gaza is evident from the speech of the key informants. It was found that each additional palliative care visit for cancer patients during the first month of follow-up increases patient functioning (Taylor et al., 2013). The findings are in parallel with what is found in literature, as there are no well-identified palliative care services in Gaza; neither specific structure nor department or pain clinic is available for this service (Abu Hamad et al., 2016). There an urgent future need for the palliative care includes initiating educational programs in palliative care nursing at the undergraduate and post-graduate levels. This should be done with integrating the palliative care, and more national and international concerns and funds for those struggling to initiate palliative care in Palestine (Khleif & Dweib, 2015).

#### **4.8.5.6** The accessibility to health information:

The accessibility to information is "the right to seek, receives and imports information and ideas concerning health issues" (WHO, 2002<sup>b</sup>).

Unfortunately, there are some gaps in the quality of the offered information to the cancer patients in general, where Anan & Abu Hamad (2013) showed that 20.1% of the primary clinics clients judged on the technical and information accessibility as good. Most of the key informants showed that there are some gaps in the quality of the offered information to the cancer patients, "Our patients in general don't receive the adequate needed health information". Moreover, he clarified, "I heard a female patient advice the other patient not to eat meat in the timing of chemotherapy, although it's known that the patient should have

a high protein diet during this period". Where some of the key informants attributed the defect due to workload and increased number of cases where they said, "We can't answer on all the patients' questions as there's overload; the number of cases is increased as you could see 100 patients per a day, which is not fair". Where other key informant added, "The overcrowdings in the daycare is the reason; you can't give each patient his appropriate time".

"The oncologists' number is not equivalent to the patients' number; they can't do the job of providing the appropriate health information"

In addition some of the key informants attributed the problem to some cultural factors the patient's relative had and said, "*The patient's relatives hide the disease nature from the patient, then I can't talk about the problem to the patient although it's right to know everything about his disease*"

Where a key informant offer a solution for the problem as he said, "Why didn't we have a clinic for a specialist, who can answer on the questions of the patients and give them advices"

"We need a system from the MOH to be forced in our hospitals, to resolve the mistaken information the patient have"

"We as the nurse department in Al-Rantisi hospital tried to resolve the problem by a personal effort, where we offer an educational brochures and liquid crystal display screen on the day care unit, where it provide some advices to the patients, and a large number of patients said that they benefited from these advices"

The majority of the participants expressed their disappointment about not receiving the sufficient information required about their disease,

Where a patient said, "There is no time for the doctor to answer my questions related to my disease" In addition, other added, "Really I don't know anything about my disease; I only knew its name!"

Other patient talked about his experience and said, "No one talked with me about the side effects of chemotherapy! till I had them" In addition he clarified, "Doctors only prescribe

me medications, I want someone to talk with me about my disease in detail, and for a lot of question I didn't have answers"

Other patient said, "We searched on internet for answers to our questions"

Whereas other said, "My relatives are doctors; I asked them all what I want"

"If I had a complaint, then my doctor can hear me, but if I hadn't, he only prescribed me the chemotherapy medications"

"I asked many doctors about my disease, I got many answers and were not the same, I lost!"

"I don't know how many cycles are still to have! No one sat with me to tell me about my disease, how to deal with it, my treatment!"

"If I didn't ask, no one can talk from himself"

It is found that the most important health information needed by the majority of cancer patients, (67.26%) concerned information on the specific type of cancer (name and stage of cancer), followed by the side effects of chemotherapy and their management (63.29%) and "prognosis (survival)" (51.8%). Periodic assessment of cancer patient's information requirements is also critical (Mekuria et al., 2016). From both the key informants and participants of focus groups, we can conclude that cancer patients did not receive the appropriate information about their real diagnosis, side effects of medications, prognosis and life expectancy and the accessible information to the patient sometimes was not complete or sufficient; sometimes it is not given by the health provider or the patient's family. As it is found that instructing the cancer patients in general with the needed health information aids the patients with decision-making, prepares them for treatment and helps them handle with adverse effects associated with it, reduces anxiety and depression and increases satisfaction with treatment (Davison & Breckon, 2012; Miyashita et al., 2015).

#### 4.8.6 Referral system abroad

The World Health Organization's constitution states: "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (WHO, 1946).

In December 2018, of 2,335 applications to cross Erez for health care, 64% only are approved, 7% are denied and 29% are delayed; 6% of the denied applications &15% of the delayed applications were for cancer patients (WHO, 2019). From the obtained results from the key informants, it showed that many times they were forced to refer patients outside Gaza due to the shortage of some facilities as radiotherapy, isotope scan or the shortage of some drugs, or in the qualified specialists in onco-surgery for some types of cancer as some of the key informants said,

"It's hard experience to have cancer anywhere in the world, hard experience to have it in Gaza Strip, It's harder when you need chemotherapy and it's absent, it's harder when you need to be referred and you can't"

"The difference between us and the outside, is that we have no specialty in the oncology, so we need to refer our patients"

The shortage of onco-surgery specialists is an important factor for the referral abroad for the colorectal cancer. The key informant explained saying,

"Referral is needed in the surgical department: as the onco-surgery is absent; some surgeries can't be done in Gaza"

"Patients are generally referred due to the lack of expertise in the field of onco-surgery. The referred patients are those who need a procedure either diagnostic or therapeutic especially the one who needs diagnostic isotope scan or patients need radiotherapy or patient need treatment by isotope".

Some of the key informants were not satisfied about the transparency of the referral system as they expressed their disappointment about the cases that did not require to be referred and they care about the cost that the patient payed during the referral journey as they said,

"The referral system is built on personal relations, doctor relations, not universal for all patients; most patients will not have the chance to be referred"

"I'm not satisfied about the referral system, we can decrease the number of cases need the referral to about 50%; the reasons for referral could be decreased" And he added, "We

have no clear system for the referral system, it's all about the evaluation of doctor, but there are fixed reasons for referral as radiotherapy and PET scan"

The burden of the referral abroad has not only the high financial effect on the MOH (WHO, 2011<sup>b</sup>) but also it has a financial burden on the patients as some of the key informants explained,

"Our patient companions need money to cover the cost of his travel, some of them begged in Al-Aqsa mosque to bring money, what is the fault of this patient? The cost to be referred is double from the cost to be referred outside"

"The referral means that the patient will lose unnecessary money (خربان دیار) for the poor patients"

Some of the focus groups participants added their comments and show their dissatisfaction about the travel cost payed by them and their companions when they are referred and whish if they had the missed services in Gaza as they said,

"To be referred is good, but the cost we need to reach to hospital is high and most of times we borrow the money and finally we are borrower"

"Why couldn't have the missing services her in Gaza, to remain between our families that we need their support"

Where some participants in the focus groups due to cultural causes supposed that the care provided outside Gaza borders is better than the care received out of Gaza as they said,

"It's known that outside Gaza, the health care is better than here, I wish if I could be referred"

"The facilities found outside are better than which found here"

Some patient comment on the hotel services, which is better in the private hospitals and in the hospitals outside Gaza, where they said,

"Because there is no possibility to do my colectomy operation in Al-Shifa hospital, I was referred internally to Al-Quds hospital, the difference between the two hospitals; Al-Quds hospital was clean, I had no psychological distress, no noise, but the nurse services was better in El-Rantisi hospital"

"I admitted in El-Hussein hospital in Jordan, and if you want to compare between European Gaza hospital and El-Hussein hospital, you will lose ( لأوروبي و مستشفى الحسين). Imagine that the food for patients was sent according to his medical status. If it's diabetic it will be totally different from the one who have hypertension"

In the other hand, some patients said that they refused the referral abroad totally as they want to be between their family members during their treatment journey as they said,

"They wrote me the referral abroad request, but I refused; I don't to be away from Gaza. My operation was done in Al-Quds hospital"

"There was a referral opportunity, but I and my family rejected it, as all the requirements I needed for my operation are found in Gaza, so why to be referred?"

"I didn't need to be referred at all, as all the requirements found in Gaza"

The referral abroad needs to be considered more from the decision makers, with the reviewing of its guidelines and principles and modifying the reasons for referral to increase the transparency of the referral abroad system. The doctors either surgeons or oncologists refer the patients for many causes related to the availability of medical equipment, investigations and medical treatment, or due to the absence of some capabilities of the health workers due to absence of training and scholarships or because of absence of needed facilities.

#### 4.8.7 Evaluation of the follow-up

Follow-up of colorectal cancer patient survivors is an essential part of management, where the Institute of Medicine and National Research Council (2005) defines the cancer survivor as "any individual currently living with or affected by a diagnosis of cancer, including family, friends, and caregivers". A focus was given to the relatively neglected period following the initial treatment and prior to the development of recurrence of disease or death (Institute of Medicine and National Research Council, 2005).

Most recurrences of colorectal cancer will happen within 2 years of surgery and 90% by 5 years. Nearly 40% of patients with stages II and III will develop recurrences, intensive postoperative follow-up strategy is recommended for them (Godhi et al., 2017). The main aim of the surveillance investigations which is done after the initial curative treatment of CRC is to improve survival through early detection of polyps or recurrent tumors when efficient treatment is possible at this stage (Goldberg et al., 1998). Secondary goals are to assess the efficacy of initial treatment, management of long-term post-treatment complications, to offer comprehensive psychologic support (Perše & Cerar, 2009). From the obtained results from the key informants, the follow-up of the colorectal cancer patients found to be weak, for that we have a high recurrence rate of aggressive colorectal cancer as they said,

"We have a high recurrence rate and this may be due to weak follow-up system, we don't know if it is resulted from the oncological treatment or the surgical treatment. We don't know where the problem is!"

"The problem that when the patient sent to the oncology department, didn't return to us in the surgical department unless there was complications as colostomy closure"

"The colorectal patient is listed under the big cancer family, which is a big problem, he has no special care in the surgical department"

"In our hospitals; the patient should take care of his doses appointment as no one will search on him (لازم المريض يجري على علاجه)"

Some of the key informants highlighted some solutions for the problem to decrease the number of recurrent cases,

"We have great problem in the follow-up of patients, It's supposed and should, if the patient doesn't come to his Follow-up date, then we should call the patient, we should have an employee special for calling the patients to remind them about their follow-up appointments. We should have follow-up for 5 years to be sure about the survival and relieving of the case"

"We should have surviving clinic in our hospitals for follow-up of cancer survivors"

"We need a special fund for the follow-up programs for the colorectal cancer to decrease the large financial costs required after the disease recurrence"

As we conclude from the key informants comments, the follow-up of the survivors of the colorectal cancer patient is very weak, and this could affect the quality of management and increase the number of recurrent cases. It is found that continuity of care after the initial treatment is ensuring the longevity and can increase the lifespan of the patients and is considered cost-effective (Denlinger & Barservick, 2009; Papagrigoriadis, 2007).

## 4.9 Evaluation of patient perspectives and satisfaction

There are many factors could affect the colorectal cancer patient's satisfaction and perspectives about the management care provided to them. Health workforces emotional & psychological support, privacy and comfortability for CRC patients in the oncology buildings, shortage of diagnostic facilities, waiting time, the timing of diagnosis, health education provided to the patients, availability of chemotherapy drugs and the success of treatment provided to the CRC patients.

In the study, nearly 40% of the patients in focus groups give a mark for the management care above five from ten; this could be related to low expectation of Gazans CRC patients and their spiritual beliefs.

" (مية من مية) The care in 100/100 (مية من مية)

"What do we need better than that"

"To the level of Gaza, this is perfect"

"Haram (حرام) the doctors and nurses here give their best!"

"The Palestinian people are poor (الشعب الفلسطيني غلبان), they agree and accommodate with any situation"

In the other hand, the other patients were dissatisfied because of absence of privacy in inpatient rooms, uncomfortable day care clinics and the prolonged waiting time in the day care clinics as a participant said, *"We need privacy, as after the chemotherapy dose we can vomit, and this is embarrassing in front other patients and their relatives"* 

Other added, "I received my last dose in the female oncology department, which was embarrassing because of insufficient beds in the male oncology department"

In addition, a patient talked with angry blaming voice and said, "When the chemotherapy doses were recommended to me, and I started my first dose of chemotherapy, they put me beside someone who is dying, as they told me this is your way (إنت على طريقه)"

Other patient added, "In inpatient clinic, there is no space, there is no enough chairs to sit (الواقفين أكتر من الي قاعدين), it's an overcrowded space"

"The inpatient clinic has no proper air conditioning or lightening"

"We need a big hall for the inpatient clinic as all the poor persons are standing, which is unbearable, My Allah resolve the situation ( (الله يفرجها علينا بس)"

Other patient talked sadly and said, "I stood waiting my turn to enter to Dr. XX for more than half an hour in the inpatient clinic till I felt dizziness and fell down"

"Even if they built another building beside this one, the problem will not solved because of the uncontrollable increased number of patients"

As it appeared from the data above, the healthcare service building quality (physical environment, communication, privacy and safety) are positively related with the patient satisfaction (Fatima et al., 2018) and the patients responded positively to pleasing surroundings and comfort (Siddiqui et al., 2015).

In addition, other patients were dissatisfied because of the disrespect from the health care providers and the absence of psychological care that should be provided to them, as they said,

"All I need is respect; I don't need my treatment if no one respects me".

"Why did the nurse XX shout on me and prevent me from seeing my Dr. XX after finishing my chemotherapy dose?"

"The nurse XX shout on me despite I'm older than his father"

"The nurses in the female inpatient department treat us badly (معاملتهم زي الزفت)

From the collected data, it appeared that colorectal cancer patients in Gaza do not have the appropriate psychological support and this could be reflected on their disease outcome.

Some patients complain from the absence of health education or proper communication with their health providers as they said,

"No one discuss with me to where I have reached in my treatment journey"

"There is no time for the doctor to answer my questions related to my disease"

"Really I don't know anything about my disease; I only knew its name!"

"No one talked with me about the side effects of chemotherapy! Till I had them"

"Doctors only prescribe me medications, I want someone to talk with me about my disease in detail, and for a lot of question I didn't have answers"

"We searched on internet for answers to our questions"

"My relatives are doctors, I asked them all what I want"

Continuous communication skills training for health providers and patient activation programs should be established to increase patient satisfaction (Azizam & SHAMSUDDIN, 2015).

Where other patients complained the absence of diagnostic facilities maintenance that could lead to long waiting time and pushing them to the private sectors, where they can't afford the cost of services as they said,

"I want to know why the CT is worked for a week then is stopped because of disruption for weeks! And they said to us go to Al-Salam center to do CT"

"I waited my biopsy pathology report for more than 1 month, a long time of thinking ( قعدت ) أبحص على النتيجة

As a summary, there are multiple factors contribute to the low satisfaction of the colorectal cancer patients; absence of privacy in inpatient rooms, uncomfortable day care clinics and the prolonged waiting time in the day care clinics, absence of psychological care, absence

of health education, absence of proper communication with their health providers and absence of diagnostic facilities maintenance.

The referral abroad, absence of radiotherapy, health care provider delay in diagnosis and shortage of chemotherapy are added factors to the colorectal cancer patients' dissatisfaction.

# Chapter Five Conclusion and recommendation

Colorectal cancer disease is considered a disease that required a multidisciplinary team to deal with it. Recently it is considered the first cancer in males and the second cancer type in females, for that it required a rapid intervention to start early screening to prevent the high number of advanced cases, which are diagnosed in late stage. This study is to evaluate the management facilities and services used for the colorectal cancer patients to identify weaknesses and gaps in a trial to modify the current situation. This chapter summarizes the results of the study findings and introduces some feasible and efficient suggestions and recommendations.

## **5.1 Conclusion**

As the evaluative studies for cancer patients' management are absent, then the perspectives and needs or such group of patients can't be raised and known. The study tried to evaluate the management of colorectal cancer patients through a lot of domains, in a trial to help in the resolution and modification of the current situation especially in the prevention and screening care.

## **5.1.1 Human resources**

Because of the political situation, the cleavage and the siege was imposed on Gaza Strip, there is no clear vision about the recruitment of human resources needed for the oncological resources especially for number of pathologists, onco-surgeons, colonoscopy specialists with absence of psychosocial experts and nutritionists. The problem is magnified by the absence of training for GPs to master how to pick colorectal cases early and scholarships (inside and outside Gaza Strip) especially for the colorectal cancer specialized surgeries that reflected on the quality of the human resources.

# 5.1.2 Service delivery

# 5.1.2.1 Buildings:

The oncology services' buildings in general are limited in space (pathology department, radiology department, day care, pharmacy and the oncology admission rooms) in both El-

Rantisi Specialized and the European Gaza hospitals that lead to overcrowdings of the patients that could lead to noise, loss of privacy, poor aeration, improper lightening, long waiting time and comfortability. All of this can be reflected on the patients' psychological aspects and can affect the quality of management.

#### 5.1.2.2 Diagnostic facilities:

The poor financing system, the absence of clear strategy for the MOH and the complex political status affect the availability, where the number of the devices are below the international ratios, absence of needed diagnostic facilities as PET scan, the limited number of diagnostic experts and augmented by the poor maintenance of the diagnostic facilities. This is reflected obviously on the quality of the received management for the colorectal cancer patients with long waiting tests for the diagnostic facilities, delay in establishing the treatment.

#### 5.1.3 Access to Essential medicines

Another domain which is affected obviously by the political situation and the absence of clear financing system is the essential medications especially the chemotherapy availability and the absence of radiotherapy totally. A lot of obstacles facing the availability of chemotherapy, where it is characterized by on and off cycles, with continuous interruption of some types of chemotherapy medications for long unpredictable period that is reflected as inability to perform any of the chemotherapy protocols and the deterioration of the condition of the colorectal cancer patients.

#### **5.1.4 Information system**

The information system for colorectal cancer includes; medical files, cancer registry and research activity faces a lot of weaknesses and gaps and needs an urgent improvement. The medical files are with non-organized archiving system with a lot of missed and lost files and badly written patient files. About the cancer registry faced problems because of absence of networking between the main health providers in Gaza Strip, absence of enough trained epidemiologists and data collectors, so the exact number of diagnosed colorectal cancer cases is not known. The research activities in Gaza is weak, is only due to sporadic individual efforts.

#### 5.1.5 Financing system

The financing system faces many challenges, as it not considered being continuous source, where the majority of financing came from donation. There is no special budget for the oncology services in general, which reflected on limited number of human resources, inappropriate buildings for cancer services and the absence of the needed number of the diagnostic facilities with improper maintenance. All of this is reflected badly on the quality of management provided for colorectal cancer patients.

#### **5.1.6 Leadership and governance**

The leadership in Palestine is not unified since along time because of the political cleavage, then there is no clear governance that can affect the decision making and planning and it considered as a barrier for applying colorectal cancer management strategies.

#### 5.1.7 Colorectal cancer management strategies

It is appeared that the colorectal cancer management strategies facing a lot of gaps and weaknesses, where the key informants argued about the presence of a clear management strategy proposed from the MOH. It could be explained that the key informants in Gaza are not involved in the administrative issues related to planning of strategies and may be due to the weak contact between the MOH in Gaza and MOH in Ramallah. The situation is also augmented by the absence of obvious network between the governmental, non-governmental and the private institutions. Moreover, the application of such strategies face a lot of problems and obstacles, where there is no obvious special financing for the oncology services that reflected as absence of the appropriate number and qualified buildings for the oncology services, non-adequate number of human resources with absence of training and recruitment and absence of oncology specialized surgeries. In addition, there is deficiency in the number of the diagnostic facilities needed for colorectal cancer diagnosis.

#### 5.1.8 Cancer management domains

The first domain for colorectal cancer management is prevention and screening, which is considered totally absent and no strategy from the MOH conclude prevention or screening program for colorectal disease. The third dimension for the colorectal management is the diagnosis, where some barriers decrease the chance of the early diagnosis of the colorectal cancer disease such as the shortages of some diagnostic facilities necessary for diagnosis. The qualifications of the health care providers play another role in the delay of cancer diagnosis due to misinterpretation of the symptoms, and poor history taking and physical examination by some practitioners. In addition, the poor health education and awareness among the population plays an corner role in decreasing the chances for early diagnosis

The fourth dimension for colorectal cancer management faces many obstacles, starting from the surgical treatment and ending in follow-up or the palliative care, For the surgical services: there are no enough specialized colorectal surgeons who can utilize advanced surgical techniques especially for metastatic colorectal cancer. Chemotherapy medications: there are serious problems in the continuity of chemotherapy treatments due to frequent unpredictable shortages in the essential drugs, which are very important obstacle for the controlling of colorectal cancer disease. Radiotherapy is not available in the Gaza Governorates. This forces the patients to be referred outside Gaza for treatment in Israel or Egypt facing a lot of suffering to reach their treatment facilities. Palliative treatment suffers from many gaps in providing the required attention to the patients suffering. This appears clearly by the absence of pain clinics, palliative surgery services and the lack of professional staff to provide such a care. The psychosocial treatment is totally absent and not included in MOH strategy in the colorectal cancer management care and health information care provided to them is not considered adequate, where the health providers cannot give the required health information because of the overload and the increased number of cancer patients.

#### 5.1.9 Referral system abroad

The referral system as a part of the colorectal cancer management domains, was created because of the absence of many services as diagnostic facilities (MRI and PET scan) and some of the needed treatments (specialized colorectal surgeries, chemotherapy and radiotherapy). The referral procedures are complex because of the prolonged waiting lists and high percentage of the rejection with a big burden on the MOH decrease the quality of cancer services provided to patients.

## 5.2 Recommendation

#### 5.2.1 Health workforces

- Recruit newly graduated GPs, psychological experts and nutritionists in the oncology department to start their work urgently and to be trained extensively to decrease the workload on the oncologists.

- Recruit international experts from other countries, which are distinguished in the oncology surgeries especially the colonoscopy colectomy for a certain period to train the surgeons in Gaza.

- Find scholarships for the colorectal surgeries, colonoscopy and palliative care

## 5.2.2 Service delivery

## 5.2.2.1 Buildings

- Developing an urgent plan to build a cancer management center through recruitment external financing sources

- Improve the current situation such as; decreasing the waiting time for the patients through organizing the visit times, providing some air conditioning sets.

- In the absence of enough buildings, encourage home care for cancer patients through primary health care programs

#### **5.2.2.2 Diagnostic facilities**

- Offer continual maintenance for the diagnostic facilities to decrease the cutting off the devices to decrease the long waiting lists

- To restart the starting plan for the Prince Naïf diagnostic center

- PET scan is a priority

#### 5.2.3 Information system

- To start a periodic and routine auditing for the quality of the medical files and reports, besides the processing of collected data and it's management and analysis.

- Train the health providers (Physicians and nurses) and the entire registry personal and unify the registration procedures using the ICD-O3 classification

- To start using a unified health care program, to establish networking between all the health providers (governmental, UNRWA, non-governmental and private)

- To Establish and empower a committee for health research and conducting additional research in colorectal cancer topics

- To encourage the researchers to conduct studies related to Gaza Strip needs

## 5.2.4 Colorectal cancer management strategy

- To review the existing colorectal cancer management strategies and sharing it between the key informants and the health providers

- To start wide dissemination of the colorectal cancer management policies and strategies

- To establish a commitment for regular evaluating and auditing the colorectal management strategies and polices

#### **5.2.5** Colorectal cancer management domains

- To enforce the prevention and screening activities for colorectal cancer in MOH

- To enforce health education programs for the colorectal cancer patients through the recruitment of a health personnel in the oncology providing services hospitals

- To train health personnel to participate in the emotional and psychosocial care for the colorectal cancer patients.

- To support colorectal cancer friends' society that can play many important roles to reduce the suffering of these patients through knowing successful treatment stories

# 5.2.6 Recommendation for further research

- Conduct research studies to explore the etiologies for the rapid increment in colorectal cases
- Carry out additional research studies to confirm the current results in large sample at national level
- Conduct a study related to the perspective and level of satisfaction for cancer patients.

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  %D8%A9#/ar/Pages/8/138/%D9%85%D8%A4%D8%B4%D8%B1%D8%A7%D8%AA%D8%B5%D8%AD%D9%8A%D8%A9. Accessed on 14/1/2019
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## Annexes

Annex (1): of Palestine& Gaza Strip (PCSB, 2011)



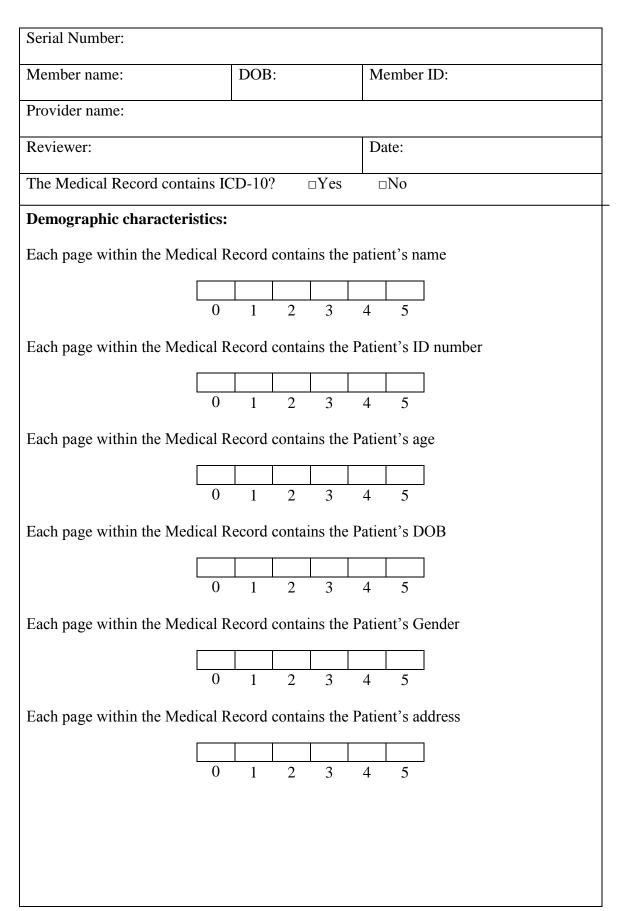
lospital name :								
Categories	No of Full time		No of Part time		No of scholars abroad		No of volunteers	
	М	F	М	F	М	F	М	F
1-Oncologist								
2- Surgeons								
3- GPs								
4-Nurses								
5-Radiologist								
6-Pathologist								
7- Psychosocial								
Others								

## Annex (2): Health workforce, diagnostic facilities & building checklists

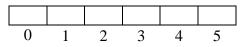
Hospital name		Hospital		••••	Hospi	ital	•••••	Hosp	ital
Facilities	No of facilities	No of Workingfacilities	Total cases / mo	No of facilities	No of Working facilities	Total cases / mo	No of facilities	No of Working facilities	Total cases / mo
				A- Imaging					
X-ray									
Ultrasound									
MRI									
CT scan									
PET scan									
Gamma Camera									
Linear accelerator									
			B- Ba	sic lab tests					
CBC									
Occult blood									
Chemistry									
Tumor markers									
			C- Diagnos	stic and Prev	entive tools				
Mammogram									
Colonoscopy									
Fluoroscopy									

Hospital Name	Inpatie	nt Ward	Daily Care Ward		
	No. of Rooms	No. of Beds	No. of Rooms	No. of Beds	
El-Rantisy Hospital					
European Gaza Hospital					
Al- Shifa Hospital					
El-Hayat Hospital					
Total					

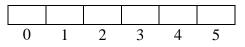
## Annex (3): CRC patients' medical records evaluation checklist



Each page within the Medical Record contains the Patient's home telephone number(s)

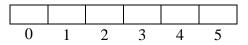


Each page within the Medical Record contains the Patient's marital status

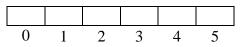


#### 1. Medical record characteristic:

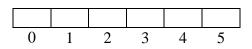
Patient's chief complaint or purpose for visit is clearly documented.



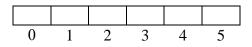
Appropriated professional diagnoses are recorded.



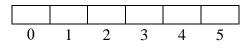
Plan of diagnosis: diagnostic tests : laboratory, radiology and pathology are listed for each visit



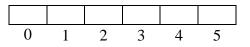
All entries in the medical record contain the author's identification.



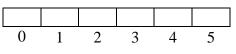
All entries in the medical record are dated.



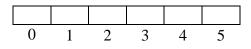
Is the record an Electronic Medical Record (EMR)?



Relevant hospital discharge summaries are included with the medical record.

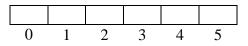


If a consultation is requested, there is a note from the consultant in the record. Consult reports reflects practitioner's review with initials or signature.

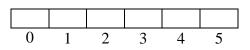


## 2. Medication Record :

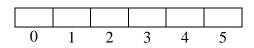
Plan of treatment: medications are listed for each visit



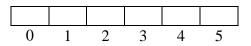
Plan of action and treatment are consistent with diagnosis.



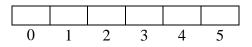
A medication record includes dosages, routes of intake and dates for initial and refill prescriptions.



Discussion of medication side effects and symptoms are reviewed with the member and documented.

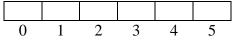


Allergies and Adverse Reactions are prominently noted in the record. Prominently noted on the front of the chart or inside the front cover of the chart or on a designated problem list or medication page or at the time of each office visit.

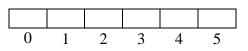


## 3. The history and physical exam

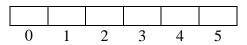
Family history - including medical history of parents and/or sibling(s)



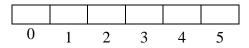
Psychosocial history



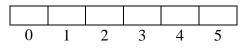
Surgical history - including serious accidents, injuries, operations.



Significant illnesses and medical conditions are indicated on the problem list

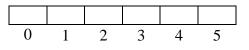


A comprehensive review of systems with an assessment of presenting complaints (as applicable).

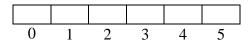


## 4. Colon cancer related characteristics

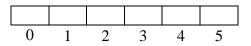
Does the morphology (histopathology) of the cancer mentioned?



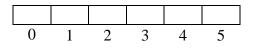
Does the behavior (aggressive- metastasis) mentioned?



Does the file contain a clear grading system for the cancer?

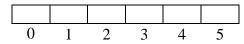


Does the staging of the cancer mentioned clearly?

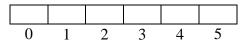


## 5. Chemotherapy record

Chemotherapy treatment plan request model has a clear diagnosis



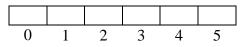
Chemotherapy treatment plan model has a clear weight and height for the patient



Chemotherapy treatment plan model has a clear body surface area

0	1	2	3	4	5

Chemotherapy plan regimen table in the request is filled



Chemotherapy regimen plan has a clear author's identification

0	1	2	3	4	5

#### Annex (4): Key informants interview questions

#### (Introduce your-self and your Research activities)

Name of interviewer:	
<b>Position of interviewer:</b>	
Name of interviewee:	
Place of interview:	
Date of interview:	
Questions:	· · · · · · · · · · · · · · · · · · ·

- Questions:
  - Being one of the Key person in health: Can you please tell me, where are we from colorectal cancer as a health problem in the Gaza Strip? (Size of the problem – public suffering – possible risk factors)
  - 2. What do you think about colorectal cancer control strategies and protocols? (*accessible- applicable- renewable*)
  - 3. Could you tell me your opinion in the current infrastructures used to diagnose and treat colorectal cancer?(*human resources training- human resources scholarships and training- buildings quality- financing stability & out of pocket payment- diagnostic facilities maintenance- diagnostic facilities experts*)
  - 4. Are you satisfied with colorectal cancer prevention activities, if any? *(Health education, screening programs)*What do you suggest?
  - 5. What do you think about the quality of care received by the patients? (*time taken for diagnosis- supportive emotional care- information- health education*)
  - 6. Can you comment on the process of Cancer cases referral (*internalexternal-satisfaction about the system-financial issue*)
  - 7. What do you think about colorectal cancer available information system and Research activities in Gaza?
  - 8. Can you talk about the major obstacles health care system face in controlling colorectal cancer?

#### Annex (5): Focus group interview questions:

#### Focus group Discussion

Group number:	Males / Females	Place: Date: /	/
- · · <b>I</b> . · · · · ·			

- 1. Please, brief me about your disease discovery. Prompt: symptoms stage family history health education before and after- screening and early detection)
- 2. How do you feel after discovering your disease? (Physical, Psychological, Social)
- 3. Could you describe your first pathway to reach the management services? (Prompt: Timing of starting treatment private clinic primary health care- secondary health care, NGOS, troubles, delay Out of pocket pay)
- 4. What do you think about your treatment and procedures performed? (Prompt: how do you feel, Physical, social, psychological context and is there any improvement after treatment)
- 5. What is your opinion about the way of archiving your medical record? (Prompt: lost, damaged, losing of some data or tests)
- 6. What is your opinion about the treating site building (Prompt: outpatient, inpatient)? (Comfortable, privacy, cleanliness, how many stars)
- 7. Tell me about the health staffs that provide care for you? (Prompt: Doctors, nurses, pharmacy, administrator, emotional support)
- 8. Those who are exposed to referral: Explain the process of referral (internal, abroad troubles delay)
- 9. Generally: Are you satisfied with the provided services?

#### Annex (6): Helsinki committee approval



# Helsinki Committee

For Ethical Approval

Name: Dalia Talaat Abd Al-Nabi Wehedi

Date: 2018/06/04

We would like to inform you that the committee had discussed the proposal of your study about: نفيدكم علماً بأن اللجنة قد ناقشت مقترح دراستكم

Number: PHRC/HC/392/18

حول:

الاسم:

#### Evaluation of Colorectal Cancer Management in the Gaza Strip

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/392/18 in its meeting on 2018/06/04

و قد قررت الموافقة على البحث المذكور عاليه بالرقم والتاريخ المذكوران عاليه

Signature

Member Member ~. () m) irman UIX **Specific Conditions:-**

#### **Genral Conditions:-**

- 1. Valid for 2 years from the date of approval? Research
- It is necessary to notify the committee of any change in the approved study protocol.
- The committee appreciates receiving a copy of your final research when completed.

E-Mail:pal.phrc@gmail.com

غزة - فلسطين قرة - فلسطين شارع النعيون



#### Annex (7): Approval letter from hospital management

# إشعار عدم ممانعة مرضى السيد/ة مراجع (ة) عيادة الأورام

لقد تم اختيارك بصورة عشوائية للمشاركة في البحث الذي أقوم به كمتطلب للحصول على درجة الماجستير في الصحة العامة من جامعة القدس-أبو ديس . تهدف هذه الدراسة الى تقييم الخدمات المقدمة لمرضى سرطان القولون في قطاع غزة من خلال الإجابة و الاشتراك في مجموعات بؤرية و الإجابة عن بعض الأسئلة:

- اشتراكك في هذه المجموعات تطوعية يحق لك القبول و الرفض
  - لا يوجد إجابات صحيحة و أخرى خاطئة
- ـ أرائك و إجاباتك لن تؤثر على الخدمات الصحية التي تتلقاها من هذه العيادة
  - السرية مكفولة لا داعى للتعريف باسمك
  - ستستغرق مدة المجموعة البؤرية ساعة تقريبا
    - المواصلات مكفولة لمن يرغب

## إشعار عدم ممانعة للخبراء

السيد/ة الخبير:

لقد تم اختيارك للمشاركة في هذا البحث الذي اقوم به للحصول على درجة الماجستير في الصحة العامة – جامعة القدس أبو ديس. تهدف هذه الدراسة إلى تقييم الخدمات المقدمة لمرضى سرطان القولون من خلال الإجابة عن بعض الأسئلة:

- اشتراكك في هذه الرسالة تطوعية يحق لك القبول أو الرفض

- لا يوجد إجابات صحيحة أو خاطئة
  - السرية مكفولة
- ستستغرق مدة اللقاء تقريبا ساعة

تقييم الخدمات المقدمة لعلاج مرضى سرطان القولون و المستقيم في قطاع غزة إعداد الباحثة/ داليا الوحيدي إشراف/ أ.د. يحيى عابد إشراف/ أ.د. يحيى عابد د. خالد ثابت ملخص الدراسة:

مقدمة

تشهد فلسطين ازديادا في معدل الوفيات لأمراض السرطان عامة، حيث تعد المسبب الثاني للوفاة بعد أمراض القلب. و يعد مرض سرطان القولون و المستقيم أحد السرطانات الأكثر شيوعا في فلسطين. حيث تفيد تقارير وزارة الصحة في قطاع غزة بأن سرطان القولون و المستقيم يحتل المرتبة الأولى في السرطانات الأكثر شيوعا في الذكور و المرتبة الثانية بعد سرطان الثدي لكلا الجنسين.

تقييم الخدمات الصحية و استراتيجيات العلاج المقدمة لمرضى سرطان القولون و المستقيم مهم لتقييم كفاءة النظام الصحي لمنع و كشف و علاج سرطان القولون و المستقيم.

هذه الدراسة هي الأولى من نوعها لتقييم الخدمات الصحية لمرضى سرطان القولون و المستقيم في قطاع غزة، على أن تساهم نتائج الدراسة في تحسين فعالية النظام الصحي في مواجهة و علاج مرض سرطان القولون و المستقيم من خلال تقديم بيانات عن كفاءة الخدمات المقدمة لعلاج هؤلاء المرضى. الهدف من الدراسة

الهدف العام من هذه الدراسة هو تقييم الخدمات و الوسائل و الاستراتيجيات العلاجية المقدمة لمرضى سرطان القولون و المستقيم في قطاع غزة.

## منهجية الدراسة

الدراسة كمية و نوعية، حيث أن الجزء الكمي اعتمد على تقييم 100 ملف طبي لمرضى سرطان القولون تم تشخيصهم خلال الفترة (2016–2017) و المسجلين في المركز الوطني لرصد الأورام و عيادات الأورام في مستشفيات قطاع غزة و اعتمد أيضا الجزء الكمي على اعتماد ثلاثة قوائم فحص بخصوص الطواقم المقدمة للخدمات الصحية في رعاية مرض سرطان القولون و المستقيم، عدد الغرف و الأسرة الموجودة في أقسام السرطان، الأجهزة التشخيصية الموجودة في قطاع غزة و المساعدة في تشخيص المرض. بخصوص الجزء النوعي تم عمل 4 مجموعات بؤرية لمرضى سرطان القولون و المستقيم.

اهم التوصيات توصى هذه الدراسة على الآتي: 1- توظيف اطباء حديثي التخرج فيقسم الأورام و القيام بتدريبهم لتقليل العبء على أطباء الأورام. 2- استدعاء اطباء دوليين خبراء في الجراحات المتخصصة في سرطان القولون و المستقيم لتدريب الجراحيين الموجودين في قطاع غزة. 3- تقديم منح دراسية خاصة بالجراحات التخصصية و جراحات المناظير الخاصة بمرضى سرطان القولون و المستقيم. 4- عمل خطة عاجلة لبناء مركز اورام للتعامل مع مرضى السرطان بشكل كامل 5- تحسن الوضع الحالي من خلال تقليل الانتظار في العيادات اليومية وتحسين التهوية في المباني الموجودة 6- توفير برنامج صيانة دوري للأجهزة التشخيصية لتقليل قوائم الانتظار في حال تعطل الأجهزة 7- بدء برنامج منح خارجية لأطباء الأشعة 8- إعادة بدء خطة تشغيل مركز الأمير نايف التشخيصي 9- البدء بالتدقيق الدوري و المراجعة الدورية لملفات المرضى 10- تدريب الطواقم الطبية و مركز الأورام على التصنيف العالمي للأمراض 11- البدء ببرنامج صحى موحد يربط جميع مقدمي الرعاية الصحة (حكومة، خاص، وكالة الغوث، مؤسسات دولية) 12- بدء مجلس للأبحاث الصحية و عمل أبحاث خاصة بموضوع سرطان القولون و المستقيم و الكشف عن مسببات الازدياد بعدد الحالات الغير مسبوق 13- تشجيع الباحثين للبدء بدراسات تبعا لاحتياجات قطاع غزة 14- مراجعة استراتيجيات رعاية سرطان القولون و المستقيم و مشاركتها مع مزودي الخدمة و أصحاب القرار 15- البدء بتشكيل لجنة خاصة لمراجعة و تعديل الاستراتيجيات المتبعة في رعاية مرضى سرطان القولون و المستقيم 16- تخليق و بدء الأنشطة المتعلقة بمكافحة و الكشف المبكر عن سرطان القولون و المستقيم في وزارة الصحة 17- تقوية و تعزيز برامج التعليم الصحى لمرضى سرطان القولون و المستقيم 18- تدريب مقدمي الخدمات الصحية للدعم النفسي لمرضى سرطان القولون و المستقيم 19-البدء و دعم جمعية أصدقاء مرضى سرطان القولون و المستقيم، لما له أثر في تقليل معاناة مرضى سرطان القولون و المستقيم من خلال القصص الناجعة في العلاج.