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# Evaluation of Pediatric Cancer Management in the Gaza Strip

**Shatha Abdalla Mohammed El-Habil**

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# Evaluation of Pediatric Cancer Management in the Gaza Strip

Prepared by:
**Shatha Abdalla Mohammed El-Habil**

BSc. of Pharmacy-Al-Azhar University of Gaza-Palestine

Supervisor: Dr. Bassam Abu Hamad

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**Thesis Approval**

# Evaluation of Pediatric Cancer Management in the Gaza Strip

Prepared By: Shatha Abdalla Mohammed El-Habil
Registration No: 21811744

Supervisor: Dr. Bassam Abu Hamad

Master thesis submitted and accepted. Date:3/1/2022
The names of signatures of the examining committee members are as follows:

1- Head of committee: Dr. Bassam Abu Hamad Signature.....

2- Internal examiner: Prof. Yehia Abed Signature.....

3-External examiner: Dr. Sobhi Skaik Signature.....

**Jerusalem- Palestine**

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**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 loving father and mother who always give me an endless source of power and encouragement and taught me to work hard for the things that I aspire to achieve.

To my lovely husband for his endless support during the challenges of study and life.

To my faithful brothers and sisters, thank you for always being with me and supporting me.

To my soul my son Mohammed.

To the family of my husband.

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

To everyone who helped me to finish this study.

Shatha Abdalla Mohammed El-Habil

## Declaration

I clarify that this thesis submitted for the degree of master is the result of my own research, except where otherwise acknowledged, and that this thesis or any of its parts has not been submitted for higher degree to any university or institution.

Signed: 

Shatha Abdalla Mohammed El-Habil

Date: 3/1/2022

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**Shatha Abdalla Mohammed El-Habil**

# Abstract

***Background and objectives:***

*Pediatric cancer is a serious problem causing an increase in morbidity and mortality and its spread is increasing in Gaza and Worldwide. This study aims to evaluate the services provided to children with cancer at Rantissi Specialized Pediatric Hospital in Gaza.*

***Methods:***

*The study design was triangulated: it involved both quantitative and qualitative approaches, The quantitative approach included administering interviewed questionnaire with caregivers of children diagnosed with cancer (210) and checking the medical records of those children (210). The qualitative approach included interviews with 12 key informants. The researcher used the statistical Package for Social Sciences version 25 for quantitative data analysis and open coding thematic method for qualitative data.*

***Results****:*

*The study revealed that the mean age of children diagnosed with cancer was 6.70 years and that 52.9% of them were males. Nearly half of children had leukemia according to what was documented in medical files and about 70.5% of participants indicated that the reason of their visit to the hospital was to conduct laboratory examinations and 69% mentioned for consultations. The majority (79.5%) of children with cancer received chemotherapy at Rantissi Specialized Pediatric Hospital, 58.6% received psychological support. Nearly 58.1% of participants reported that there are shortages in diagnostic tests and 23.8% reported that there are shortages in laboratory tests in Rantissi Specialized Pediatric Hospital. Most of children with cancer (84.3%) received pediatric cancer services at more than one place: local hospitals in Gaza and referral outside Gaza as 75.5% of children with cancer in this study got chemotherapy outside Gaza. Results of the study showed that there are gaps in service provision including inadequate human resources such as. limited number of pediatric oncologists, no oncology specialized surgeons, no nutritionists. There are protocols for pediatric cancer management, however, the application of these protocols is hindered by shortage of resources. The infrastructure of pediatric hematology and oncology department is appropriate, the department is equipped with modern and up-to date equipment and the physical built up of the place is comfortable and suitable for children. Most of pediatric referrals are due to immunotherapy such as monoclonal antibodies, diagnostic reasons, surgery and radiotherapy and usually constrained by the Israeli occupation policies. There are shortages in some essential medicines as PEG-asparaginase, L-asparaginase and procarbazine, rituximab and monoclonal antibodies. The mean time generally to receive services from entry to the exit of the hospital was 116.7 mins. Medical file documentation completeness average was 59.99%. User-provider interactions mean percentage score is 81.7% and the satisfaction mean percentage score about provided services is 81.4%. However, using strengths and difficulties questionnaire, the study showed that 50% of children were rated as having psychological issues. Children whose fathers are working, having better income and diagnosed for more than 3 years showed better scores in the strengths and difficulties scale and the differences between them and their counter groups were statistically significant.*

***Recommendations***

*Enhancing policies for pediatric cancer management and improving the diagnostic facilities and human resources for pediatric cancer management is essential. It is important to improve the health information, cancer registry and research studies related to pediatric cancer management and also promoting psychological care.*

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## List of abbreviation

| | |
|---|---|
| **ACS** | American Cancer Society |
| **CT** | Computerized tomography |
| **EMR** | Electronic Medical Record |
| **FISH** | Fluorescence in Situ Hybridization |
| **GP** | General Practitioner |
| **HIS** | Health Information System |
| **Ibid** | The Same Previous Reference |
| **IARC** | International Agency for Research on Cancer |
| **MDR** | Minimal Residual Disease |
| **MOH** | Ministry of Health |
| **MRI** | Magnetic Resonance Imaging |
| **NGOs** | Non-Governmental Organizations |
| **ODI** | Overseas Development Institute |
| **OECD** | Organization for Economic Co-operation and Development |
| **PAHO** | Pan American Health Organization |
| **PCBS** | Palestinian Central Bureau of Statistics |
| **PET** | Positron Emission Tomography |
| **QOL** | Quality of Life |
| **RSPH** | Rantissi Specialized Pediatric Hospital |
| **SDQ** | Strengths and Difficulties Questionnaire |
| | the Near East |
| **UICC** | Union for International Cancer Control |
| **UNICEF** | United Nations International Children's Emergency Fund |
| **UNRWA** | United Nations Relief and Works Agency for Palestine Refugees in |
| **WB** | The World Bank |
| **WHO** | World Health Organization |
| **WSR** | World Age Standarized Incidince Rate |

# Chapter One

## Introduction

Worldwide Cancer is the second leading cause of death behind cardiovascular disease (Wang & et al. 2016). In 2020, it was estimated that there were 19.3 million new cancer cases and about 10 million deaths (Sung, 2021). Globally, approximately 400,000 children aged 0 to 19 years old are diagnosed with cancer yearly and age- standardized incidence rate (WRS) was 140·6 per million person-years in children aged 0-14 years. In addition, the most common cancer was leukemia (46·4 per million), followed by CNS tumors (28·2), and lymphomas (15·2) (Steliarova-Foucher & et al. 2017).

The most types of cancer in United State during childhood period (0-14) are as the following: leukemia which is the most common type of cancer in children, accounts for 28% of all cancers in children, brain and other central nervous system cancers follow leukemia and represent 26% of childhood cancer, neuroblastoma accounts for 6% of all pediatric cancer, Wilms' tumor (5%), Non Hodgkin lymphoma (5%) and Hodgkin lymphoma (3%), rhabdomyosarcoma (3%), bone cancer (3%) and retinoblastoma (2%) of all cancer in children (American Cancer Society, 2019a). Pediatric cancer has different risk factors, ionizing radiation, chemicals and drugs, biological factors, genetic and familial factors and age (Pan American Health Organization, 2014).

The physical symptoms of cancer and treatment in children are associated with psychological, social and academic impairment. Children with cancer and child cancer survivors may experience: severe anxiety, depressive and withdrawn behavior, behavior problems, excessive physical complaints, extreme stress, post-traumatic stress disorder (PTSD), peer relationship difficulties, fears about the future in relation to job and relationships and academic difficulties due to absenteeism, which may result from hospitalizations, treatments, and treatment side effects (Toro, n.d). The families have financial burden associated with care of children with cancer in particular in transportation, communication, housing, health and food (Velandia & Moreno, 2018).

In Gaza, in the period between 2016-2020, the rate of pediatric cancer increasesd to 7.7%.. Leukemia was the most common type of pediatric cancer, while brain cancer was the

second type of cancer in pediatric (Annex 8). According to (ACS, 2019b), pediatric cancer can be treated by surgery, radiation, chemotherapy, targeted therapy and immunotherapy depending on the cancer type and stage and some types of childhood cancers can be treated with high-dose chemo followed by a stem cell transplant. Pediatric cancer management in children's cancer centers follow a multidisciplinary approach, in which pediatric cancer treated by a team consisting of pediatric oncologists, pediatric surgeons, oncology nurses, nurse practitioners, radiation oncologists and physician assistants (ACS, 2019b). Cancer is more likely to be curable and respond to effective treatment, if it diagnosed early (World Health Organization-WHO, 2002a)

## 1.1 Research problem

According to MOH (2021), In the Gaza, pediatric cancer during 2016-2020 constituted 7.7% of all cancers (Annex 8). Leukemia, brain cancer, bone cancer, lymphoma and neuroblastoma are the most common types of cancer in children (Ibid). This gives the researcher an alarm to think deep to the evaluation of pediatric cancer management. There is information gap about pediatric cancer services in terms of input, processes and outcomes with most studies focused on adult cancer and there are no studies have been carried previously on this topic. Therefore, the need for this evaluation is particularly acute. This study will be the first to evaluate pediatric cancer management in Gaza in order to identify positive points in provision of pediatric cancer services and to explore the gaps in order to promote the services are provided to children with cancer, improve quality of life and decrease morbidity and mortality for pediatric cancer cases.

## 1.2 Justification

Due to severity of cancer disease, the health care services that are provided to children with cancer should be adequate with high quality. No enough studies have been conducted about management of pediatric cancer, and this study focused particularly on this field. Good management of pediatric cancer needs appropriate political situation, early diagnosis, protocols development & application, appropriate and sufficient resources, diagnostic tests and essential drugs, good user-provider interaction and adequate pediatric cancer research.

In order to enjoy good quality of life we need strong pediatric cancer management that will detect early pediatric cancer, decrease morbidity, promote high quality physical, psychological and social wellbeing of all children with cancer and increase survival rate.

In this study the researcher will provide a review for the available services and strategies for management of pediatric cancer in the Gaza Strip to cover over the strengths and weakness, thus will benefit the health care system by increasing the awareness of any weakness in services and strategies for cancer management and improving the quality of life for pediatric cancer survivors. The results of this study will use to inform and guide decision makers and health providers to develop strategies and promote the quality of provided services for pediatric cancer management, thus enhancing the quality of life for pediatric with cancer and decreasing the morbidity and mortality rate in pediatric cancer cases. They may provide insights for donors which engaged in promotion of pediatric cancer services for better planning. They would add some important parts to the research field of cancer in general to reach the needed level of international standards. Moreover, this study is valuable to the researcher herself as being involved in this field and provides her with a rich background about cancer management and may bring benefit to researchers regarding the same topic by giving them idea about how to evaluate the management of services.

## 1.3 Aim of the Study

The aim of this study to assess the status of services provided for children with cancer in order to explore the gaps in services, and provide recommendations to improve services in order to decrease morbidity and mortality among children with cancer.

## 1.4 Objectives

- To assess the status of services for pediatric cancer, using Donabedian model (input/ process and output/ outcome) in the Gaza strip.
- To identify the areas of strength and weakness related to services are provided for children with cancer
- To explore perspectives (users and providers) about services provided to children with cancer.

- To explore variation in patients' perspectives and experiences in reference to characteristics and disease related variables.
- To suggest some recommendations to improve the approach of cancer diagnosis and management.

## 1.5 Research questions

1- Are there effective services being available for children with cancer?
2- To which extent the inputs related to services for pediatric are available?
3- How is the pediatric cancer services functioning?
4- What are the areas of strength and weakness related to services are provided for children patients with cancer?
5- How do clients and service providers perceive the pediatric cancer services in Gaza?
6- What is the current access status for pediatric cancer services from clients' perspectives?
7- What are the most important factors that indicate good quality of services from client perspectives?
8- Do the available services and resources meet the expectations of health care providers, children with cancer and their caregivers?
9- Do pediatric cancer services have an impact on the wellbeing and QOL of children with cancer?
10- How much does the pediatric cancer services contribute to the quality of life and wellbeing of children with cancer?
11- What are the crucial factors that could affect decision maker choices regarding cancer management?

## 1.6 Context study

### 1.6.1 Gaza

Palestine is located at the Eastern Mediterranean Sea. Mediterranean Sea bordered Palestine from the west, Jordan bordered Palestine from the east, Syria and Lebanon bordered Palestine from the north, Aqaba Gulf from the south (Ministry of Foreign Affairs and Expatriates, 2019). The Gaza Strip is part of Palestine. It is a densely populated zone with an area of 365km$^2$ (Palestinian Central Bureau of Statistics-PCBs 2021a). The Gaza

Strip includes five governorates, north Gaza, Gaza, Mid Zone, Khan Younis and Rafah. The total population of Palestinian in West Bank and Gaza in end year 2020 was about 5.2 million, 2.62 million males, 2.54 million females, 2.1 million of them in the Gaza Strip. (PCBs, 2021a). The life expectancy in the Gaza strip for males is 72.5 years and for female is 74.7 years and population of the Gaza Strip is characterized by the dominance of age group below fifteen years old with a rate of 41.4% (PCBs, 2019) and 50% under the age eighteen (WHO, 2017a). According to (PCBs, 2021a) the unemployment rate in the Gaza Strip 46.6%. The average household in the Gaza Strip is 5.5 persons and the population density about 5693 individual/$km^2$ (Ibid).

### 1.6.2 Health Status and Health care system

Non-communicable diseases are the major causes of morbidity and mortality for Palestinians (WHO, 2017b). The prevalence of non-communicable diseases leads to significantly premature death and reduced healthy life expectancy (Ibid). In 2020, ardiovascular diseases are considered the main leading cause of deaths in Palestine, as they recorded 24.7% of total deaths in 2020, followed by diabetes mellitus with 14.6%, then cancer with 14.1% from total deaths in Palestine (MOH, 2021a).

In 2015-2019 the mortality rate of children <5 years in Gaza was 14 per 1000 births, the infant mortality was 13 per 1000 births and the child mortality rate was 15 children per 1000 live births (PCBs, 2020). The health system in Gaza is composed of primary, secondary and tertiary care. Service providers include the MOH, United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), Non-Governmental Organizations and private sector (NGOs). MOH is considered the main health services provider in Gaza, which provides holistic services for population, primary, secondary and tertiary health services and purchases unavailable tertiary health services for the needed patients from domestic and foreign providers, UNRWA provides primary health care for refugees only and purchases secondary care services for needed patients , NGOs provide primary, secondary and some tertiary services depend on projects and funds and private sector provides primary, secondary and tertiary care services through of specialized hospitals and investigation centers (WHO, 2014).

The financial situation of the MOH leading to shortage of staff, salaries, drugs, supplies, training opportunities (Health Cluster, 2014). The total number of hospitals in the Gaza Strip is 36, 14 of them MOH hospitals, the total number of primary health clinics is 159 and the number of hospital beds is 3338 with rate of 16.1 beds for each 10,000 of population (MOH, 2021b). The main hospital responsible for pediatric cancer services is Rantissi specialized pediatric hospital. There are many facilities for diagnosis and treatment of pediatric cancer, but in other hand also, there are many of facilities for diagnosis and treatment are not available, which leads to costly referrals of patients outside of Gaza.

### 1.6.3 Palestinian cancer registry

Cancer registry is defined as a system which includes collection, storage, analysis, interpretation of data collected on persons with cancer and share the answers to these questions with other groups (Centers for Disease Control and Prevention-CDC, 2015). The Palestinian cancer registry center was established in 1996 by the cooperation between MOH and Middle East cancer consortium in both Gaza strip and West Bank and has published annual reports since 1998. The registry's main objective is to determine the cancer burden in the region and determine cancer incidence, prevalence, and mortality (Gale & Halahleh, 2018). The main sources of data collection are, governmental hospitals, governmental and private histopathological center, governmental and private radiology centers, referral abroad and death certificates (MOH, 2016). In Gaza, the main center for Palestinian cancer registry in Gaza city to cover north of Gaza, Gaza city and the middle zone and the second branch in European Gaza hospital and covers Rafah and Khan Younis.

### 1.6.4 Rantissi specialized pediatric hospital (RSPH)

Rantissi specialized pediatric hospital established in 2006. The oncology pediatric department was established in El-Nasir Pediatric hospital and was transferred to RSPH in 2008. In 2015, temporarily adult oncology department was transferred from Al-Shifa hospital to RSPH until oncology department at Al-Shifa hospital to be finished and ready for serving cancer patients. Recently the hematology and oncology department for pediatric cancer has been opened in RSPH in February in 2019 and is considered as the second largest department for treating cancer in Palestine (MOH, 2019a). This department in RSPH accommodates 31 beds, 15 beds for daycare and 16 beds for hospitalization, three

examination rooms, a clinic for daycare, laboratory, chemotherapy pharmacy and playing room (MOH, 2019b). Three doctors are working in this department divided on outpatient clinic and main department.

## 1.7 Operational definitions

- **Child**: in this study child is anyone who is less than 12 years, because for culture reasons children over 12 are treated with adults.
- WHO defines Quality of Life (**QOL**) as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment"
- **WSR**: Age- standardized incidence rate using the World global standard population (expressed as the number of new cases per 100,000 person years) (Belgian Cancer registry, 2021).
- **The Strengths and Difficulties Questionnaire (SDQ):** is a brief behavioral screening questionnaire. It exists in several versions This version for the children above 4 years. The total difficulties score result includes emotional, conduct, hyperactivity and peer scores. The total difficulties score from 0-13 reflects no significant problems, 14-16 may reflect clinically significant problems and 17-40 reflect a substantial risk of clinically significant problems in this area (Department of Health and Ageing, 2003).

# Chapter Two

## Conceptual framework

### 2.1 Conceptual framework

The conceptual framework was constructed after reviewing the relevant literature for pediatric cancer management. The figure 2.1 demonstrates the major variables which are affecting the pediatric cancer management quality. The conceptual framework of the study was adopted from Donabedian model linking structure, process and output/outcomes. There are other factors beside the main domains which have influential effect.

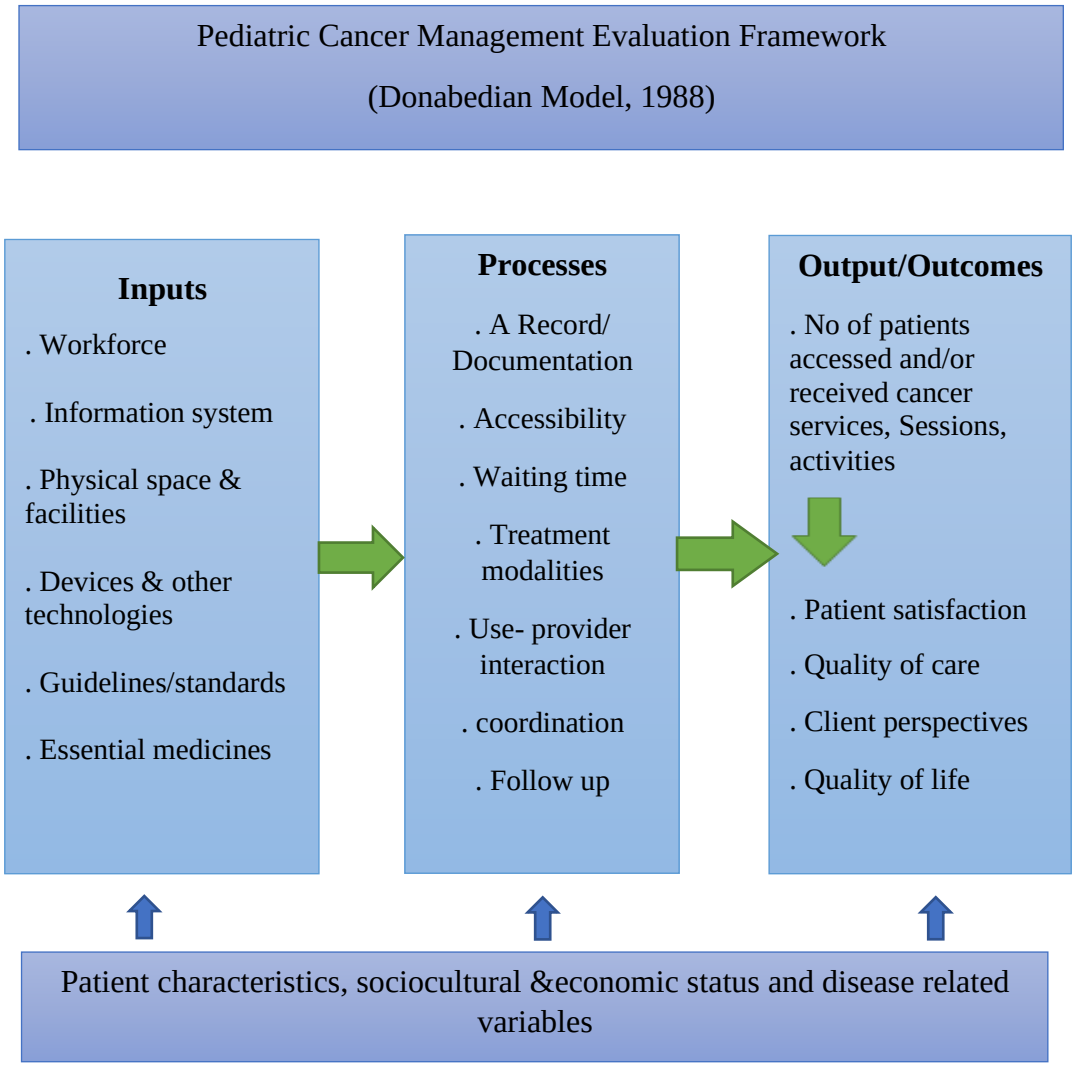


**Figure (2.1) Conceptual framework of the study**

### 2.1.1 Inputs/Structures

Inputs/ Structures include main requirements for good performance of pediatric cancer management. Here the researcher focused more on the facilities level and the context in which care is delivered. Input/structure includes workforce, information system, devices and other technologists, physical space of facilities, guidelines & standards and essential medicines.

#### 2.1.1.1 Workforce

Health workers are all people engaged in work whose primary aim is the promotion of health (WHO, 2006). The researcher examined availability of sufficient number of staff, distribution, their skills, if the profession is regulated by state, if they are well paid as well as availability of incentives. The adequate number of highly qualified workforce are related to good process and effective output.

#### 2.1.1.2 Information system

The researcher evaluated if there is database; if there is infrastructure (soft or hardware format), if it is valid, reliable and timely produced, if there is ability to analyze, disseminate and use of information and the researcher assessed whether there is information on how many pediatric require services, of what type and where they live.

#### 2.1.1.3 Physical space of facilities

The researcher explored availability and distribution of facilities, if accessibility is ensured, including physical building and informational accessibility, if there is enough space for provision of services. Facilities should contain areas for waiting, diagnosis, treatment, counselling, activities and medication dispensing and should contain and accessible toilets and the researcher assessed furniture, cleanness and if privacy and confidentiality are insured and if the nature of the place is suitable for children.

#### 2.1.1.4 Devices and other technologies

The availability of diagnostic equipment and materials or reagents used to perform some diagnostic tests in terms of their number, types, their quality, safety, efficacy and cost effective.

#### 2.1.1.5 Guidelines/standards

All steps in the services delivery should be based on evidence and should be compatible with local, national and international standards. The researcher explored if there are available guidelines, protocol and if they being applicable and effective.

#### 2.1.1.6 Essential medicines

The availability of essential medicines can save lives and maintain health. It should be available, affordable, of high quality and used properly (WHO, 2002b). The researcher assessed the availability, affordability and accessibility of essential medicines, if there are chemotherapy protocol and standardized protocol for drugs, if the insurance covers the costs of essential medicines to reduce out of pocket especially for poor, assessed if there are selected properly based on patients and population real needs. Availability of essential medicines is related to high quality outcome.

### 2.1.2 Processes

The process reflects the way your systems and processes operate to achieve the desired outcome (National Health Service Improvement, n.d.). It refers to what is actually done in giving and receiving care (Donabedian,1988) or it is the sum of actions make up health care. According to Donabedian (2003), the measurement of process is approximately equivalent to the measurement of quality of care due to process contains all acts of healthcare delivery.

Process includes records or documentation, accessibility, waiting time/ appointment system, Treatment modalities, user and provider interaction, coordination and follow up.

#### 2.1.2.1 Records/ documentation

A Record is considered a very important document to monitor progress and follow up of patient. The researcher checked the availability of a record for every patient, if records are written clearly, check if records are completeness, assessed if the clinical records are kept secure and if there are electronic medical files.

#### 2.1.2.2 Accessibility

The treatment journey from diagnosis to drug dispensing was explored whether it was smooth, unclear or full of obstacles. The researcher also assessed if there is effective referral abroad in these times, and if not, what are obstacles prevent the referral abroad.

#### 2.1.2.3 Waiting time/ appointment system

Appointment system ensures compliance to the planned appointment to ensure no patient is left behind. Timely pediatric cancer service provision is important to decrease cancer complications and to improve cancer outcomes, waiting time can be measured during the diagnosis, patient's follow-up and during the dispensing of drugs from the pharmacy.

#### 2.1.2.4 Treatment modalities

The researcher assessed the availability and application of the different treatment modalities as chemotherapy, immunotherapy, surgery, radiation and a bone marrow transplant.

#### 2.1.2.5 User -provider interaction

It is the communication behavior between patients and providers, the researcher assessed if the relationship between health care provider and child's caregiver is good and if respect of patients and their caregivers is ensured, if staff committed to treatments, if needed information is transferred to patients correctly through awareness as how to live with their disease, how to take medicines, and the researcher assessed if the privacy and confidentiality of patients is respected.

#### 2.1.2.6 Coordination (provider-provider interaction)

The researcher explored the extent of coordination between different health care providers (e.g physicians, nurses, pharmacists, ……..,…etc). if the service is divided, if it is difficult to move from one place to another or if there are different protocols from one place to another.

#### 2.1.2.7 Follow-up

Follow-up is needed to review outcome. Follow up includes regular physical examination or medical tests or both. Follow up improves outcomes and is an important part of service delivery. It includes who does the follow up, the provider or referrer etc.

### 2.1.3 Output/Outcome

Output and Outcomes are influenced by inputs and processes. Outcome reflects the effects of care on the health status of patients and the population (Donabedian, 1988) or the effect on the patient and demonstrate the end result of improvement work and whether it finally achieved the aim (National Health Service Improvement, n.d). Output includes Number of patients accessed and/or received cancer services and outcome includes satisfaction and quality of care.

**Output:**

#### 2.1.3.1 Number of patients accessed and/or received cancer services

Number of children with cancer accessed and/ or benefited from cancer services reflects the capacity of the system.

#### 2.1.3.2 Sessions

The researcher examined the number of sessions provided including consultations, psychological and follow up sessions.

#### 2.1.3.3 Activities

The researcher explored how frequency patients visited the hospital, how many visits for each patient and how many cases does the doctor see daily.

**Outcome:**

#### 2.1.3.4 Satisfaction

The researcher assessed patient's caregiver feedback on services if they meet their expectations or not which include diagnosis, pathways, waiting time, user provider

interaction, staff interaction, responsiveness of the service and quality of care, child's health status, follow up, medication dispensing and patient's caregiver involvement.

#### 2.1.3.5 Quality of care

The researcher investigated the extent of services provided to patients improve desired health outcome. The researcher assessed the service availability and accessibility. The quality of care affected by inputs and processes.

#### 2.1.3.6 Client needs and perspectives

Client needs and perspectives factor indicates to the extent of responsiveness of health care, also indicates to involvement of clients in planning and evaluating of health care services. The researcher tried to knowing the important factors that indicate to good quality of services and the extent of pediatric cancer services are provided meet these factors. the researcher assessed the patient's perceived impact of the services on their health status.

#### 2.1.3.7 Quality of life

The researcher assessed feedback impact of the services on their children quality of life, including their perspectives on their children health, how they feel in life, social relationships.

### 2.1.4 Influencing factors

#### 2.1.4.1 Patient characteristics

There are other factors that might have an influence on the provided service, such as demographic characteristics, sex, age, area of residence, medical and health condition and any associated illness.

#### 2.1.4.2 Sociocultural & economic status

These factors have an influence on the provided service such as, the belief that cancer is incurable, cancer treatment is pain and may lead to death, fears from alienation from family or community due to morbidity resulting from cancer treatment. Economic status of patient's families influences on the services such as income, occupation and poverty.

#### 2.1.4.3 Disease related variables

Disease related variables include, age of patient, cancer type, site of cancer, age of disease, complications related to disease, if patient received treatment or not and treatment side effects.

## 2.2 Literature Review

### 2.2.1 Overview of cancer

Cancer is a generic term for a large group of diseases, occurs in people of all ages, that can affect any part of the body. Cancer is the rapid formation of abnormal cells that grow outside their usual boundaries, and which can then invade adjacent parts of the body and spread to other organs and causes morbidity and mortality if left untreated (WHO, 2021a).

Globally, Cancer is a leading cause of death in all countries. The number of cancer cases and deaths is expected to increase rapidly with population growth, and adopt risky lifestyle behaviors that increase cancer risk (Toree and et al, 2016). Cancer, when diagnosed early, is more likely to respond to effective treatment, resulting in a greater likelihood of surviving and reduced disease and lower treatment costs (WHO, 2017a). Cancer is considered a "disease of affluence"--a disease that mostly affects people in the wealthiest countries, but today's infographic shows, the reality is not so straightforward: In the United States the rate of lung cancer is twenty-six times higher than it is in Tanzania, but Tanzania's rate of cervical cancer is nine times higher than that of the United States. The geographic pattern of cancer depends on lifestyle and the power of preventive measures (Elert, 2012). In the Gaza, the cancer is considered the second major cause of morbidity and mortality after heart disease (Abu-Hamad, Skaik & Abu-Oda, 2016). According to MOH (2021), 8903 cases of cancer were registered during 2016-2020 and there is an increase in the incidence rate of all cancers as the incidence rate of all cancers in 2016 was 89 per 100,000 and 90.8 per 100,000 in 2020 (Annex 8). The most common of cancer types among Gaza population are breast, Colorectal, leukemia, lung and thyroid cancers (Ibid).

Cancer services in the Gaza Strip characterized by instability, incompleteness, lack of most needed cancer services, lack of most essential therapies, absence of training, weak referral system, absence of some areas in cancer surgery such as palliative surgery and the surgery of some types of cancer (Abu Amer, 2012).

### 2.2.2 Pediatric cancer

Unlike cancer in adults, the majority of childhood cancers do not have a known cause, but very few cancers in children are caused by environmental or lifestyle factors (WHO, 2021b). Inherent risk factors including birth weight, parental age, and birth defects as well as common genetic variation are consistently related to childhood cancers (Spector and et al, 2015). Some children inherit DNA mutation that increase their risk of certain types of cancer from a parent but most of cancer result of acquired mutation of DND that happen early in the child's life or before birth, the causes this mutation in most childhood cancer are unknown. Some may have environmental causes like radiation exposure and others with unknown causes. But it is likely that many of them are the result of random events that sometimes occur inside the cell without external causes (ACS, 2019c).

According to PAHO, (2014), the most frequent cancers in children <5 years are: leukemia, neuroblastoma, Wilms' tumor, testicular tumors and retinoblastoma. The most frequent cancers in children 5- 10 years are: Leukemia, non-Hodgkin's lymphoma, Hodgkin's lymphoma, tumors of the CNS and soft tissue sarcoma and the most frequent cancers in children > 10 years are: leukemia, non-Hodgkin's lymphoma, Hodgkin's lymphoma, tumors of the CNS and Germ cell tumor. Although the male-to-female (M:F) age-adjusted incidence is > 1.0 for all types of leukemia and lymphomas, there is a higher incidence of acute lymphoblastic leukemia (ALL), Non-Hodgkin's lymphoma, Hodgkin's disease, ependymomas, primitive neuroectodermal tumors and acute lymphoblastic leukemia (ALL) in males, and a higher incidence of thyroid carcinoma and malignant melanoma in females (Linet, Wacholder & Zahm, 2003). When cancer is diagnosed early, it has a chance to respond to effective treatment, improve survival, reduce suffering and result in less intensive and expensive treatment (WHO, 2021b). Pediatric cancer is treated with standard therapies as chemotherapy, surgery or radiotherapy and children with cancer require a dedicated, multi-disciplinary team to provide also attention to their ongoing physical, cognitive development and nutritional status. The access to pediatric cancer services as effective diagnosis, pathology, blood products, essential medicines, pathology, blood products, radiation therapy, technology and psychosocial care is variable and unfair around the world (Ibid).

### 2.2.3 Pediatric cancer epidemiology

Worldwide, every year, the number of children aged 0-14 years who are diagnosed with cancer exceeds 200,000, four fifths of whom live in low-income countries. In the last decades, at least at least in high-income countries, the incidence of pediatric cancer has increased (Terracini, 2011).

In 2015, globally, the total of cancers occurring for children aged (0-14) was 360,114, included additional cases, especially those that might remain undetected in the areas where a large proportion of the population is exposed to endemic P. falciparum infestation and those that could be diagnosed in a well-functioning health system, 54% of children with cancer cases in Asia and 28% in Africa and children with cancer rates ranged from 178 cases per million in Europe and North America, through to 218 cases per million in West and Middle Africa (Johnston & et al, 2020).

Worldwide, in 2001 -2010, the average annual incidence in children aged 0-14 years was 140 new cases per million children and the most common childhood cancers are leukemia and lymphoma (ACS, Union for International Cancer Control, International Agency for Research on Cancer, 2019). Pediatric cancer is the second leading cause of death among children ages 1 to 14 in United State, about 1,190 children under the age of 15 are expected to die from cancer in 2021(ACS, 2019d). In 2014-2016 the incidence rates of cancer for children Aged 0 to 4 years in United states was 226.9 per million, 123.7 for children aged 5 to 9 years and 151.3 per million for children aged 10 to 14 years per million (United State Environmental Protection Agency, 2019).

At the regional level, the annual age-specific cancer incidence rate for children aged 0-14 years in Saudi Arabia is 99.83 per million population. lymphoid leukemia is 25.75, 12.05 for brain tumors, and 9.82 per million for Hodgkin lymphoma (Belgaumi & et al, 2019). The overall cancer incidence rate in Alexandria increased from 1972 to 2001, as the incidence of lymphatic and hematopoietic cancer in 2001 have increased nearly 11 times cancer incidence in 1972, the incidence of leukemia in infants less than 5 years increased significantly with a higher incidence among boys, incidence of Genito-urinary cancers increased by 3.7 times the incidence of cancer in 1973 and brain and central nervous system cancers increased by 4.5fold the incidence of cancer in 1973 (Hosny & Elkaffas, 2002).

Locally, in Gaza according MOH (2020) report, the number of children <18 years who were diagnosed with cancer in 2015-2019 is 653, which constitute 7.6% from all cancer and the number of children aged (0-14) is 454, which constitute 5.6% from all diagnosed with cancer in 2015-2019 (Annex 6,7). Pediatric cancer in children <18 years constituted 7.7% of all cancer in 2016-2020 (Annex 8). Pediatric cancer is increased, as in period 2015-2016, the cancer cases for children <18 were 6.3% of all cancer (MOH& PHIC, 2016).

### 2.2.4 Pediatric cancer survival

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). The survival rate of pediatric cancers has increased since the 1970s and has reached nearly 80% in high-income countries. Now, children with cancer can be successfully treated and cured. But, access to the best treatment varies greatly between countries due to the uneven distribution of resources for cancer care (Terracini, 2011).

In developed countries, more than 80% of childhood cancer patients survive 5 years after they are diagnosed, but in many low-income countries, the outlook is much less favorable due to suboptimal access to care, late diagnosis, therapy abandonment, inadequate of treatment and the financial challenge (ACS, UICC, IARC, 2019). In United States the overall mortality rates for children with cancer have lowered and survival has improved. Mortality rates reduced for leukemia and lymphoma but didn’t change for bone, brain, and soft-tissue cancers, and in the period from 2001-2007 to 2008-2015, the survival rate increased from 82.0% to 85.1% (Siegel & et al, 2020). Improvements in childhood cancer outcomes may depend on access to care, improved treatment and supportive and long-term care (Ibid). According to ACS (2019e), There is significant increase in survival rate with 84% of children with cancer survive 5 years or more while the survival rate was 58% in the mid-1970. Survival rate for children with cancer aged 0-14 years is reported as 79.1% in all Europe, 82.1% in southern Europe, and 70.2% in Eastern Europe (Gatta & et al, 2014) and 5-year survival for children with cancer aged 0 to 14 years diagnosed in Turkey in the period from from 2002 to 2008 was 65%, and improved to 69.5% during 2009-2016 (Kutluk & yesillipek, 2017). The survival rate for pediatric cancer varies greatly by region, particularly poor survival in Africa. Although expanding access to treatment methods as

chemotherapy, radiation, and surgery and addressing financial toxicity are essential, investments that enhance the quality of care, at the health-system and facility level, , are essential to promote pediatric cancer outcomes globally (Ward & et al, 2019).

### 2.2.5 Health Workforce

Health workers include doctors, nurses and other health care professionals to provide high-quality health care to individuals and communities (WHO, Organization for Economic Co-operation and Development and World Bank, 2018). Truth (2013) realized that there is no health without workforce, and found many of issues that may of countries suffered from them, such as there are lack of some categories of health workforce, the workforce ageing and replacement is a challenge and there is wide variation between countries in availability and accessibility of workforce due to difficulties in attraction and retention of workforce.

To ensure health workforce availability, accessibility, retention and workmanship, this needs to motivate the health workforce in a favorable environment,, estimation of future needs for health workforce, performance assessment, quality of life should be afforded a priority, human resources information and data require strengthening, to meet the needs of decision makers and investment and performance assessment (Truth, 2013).

WHO mentioned some aspects of health workforce support such as, planning, education, retention, management and incentives (WHO, 2016). According to (WHO,OECD and WB, 2018), to ensure the provision of high-quality health care services, many aspects should be considered when talking about workforce like adequate numbers of health workers, accessibility of patient to see and speak with health care provider with the right skills, acceptability indicates if whether people feel they have been treated with respect, and their opinions are taken into consideration when the decisions are related to their health skills mix and teamwork spirit and the knowledge and skills needed to manage local mortality and morbidity, quality, attitudes of health care provider according to accepted norms, and as perceived by users, favorable environments including the physical, organizational, legal, financial, political and cultural conditions that support high-quality care. Healthcare workforce shortage influences on healthcare access in rural communities. A shortage of healthcare professionals can limit access to healthcare by reducing the supply of available services as in areas located in rural areas (Rural Health Information Hub, 2017). One of the

challenges that facing promotion the cancer care in Palestinian territories is shortages of cancer specialists, skilled nursing staff, medical staff and training (Halahleh & Gale, 2018).

### 2.2.6 Information system

Health information system helps to easily access to patient information, improve documentation and reduce errors and lost data. There are many barriers to implementation and use of health information system, the first is technical which represented by inadequate planning for implementation and use of HIS, the second is organizational which represented by insufficient facilities for fast and easy access to the Internet, the third is personal which represented by insufficient awareness of healthcare providers about the advantages of HIS and the fourth barrier is legal and ethical which represented by concern about the security and confidentially of HIS (Malekzadeh et al., 2018) . The study conducted by Ahmadian, (2017) indicates that the most common challenges to use health information system in hospitals are negative attitude of the society toward using HIS and absence incentive to use system.

### 2.2.7 Physical space of facilities

Physicians, architects, and hospital managers think that the hospital build environment can benefit the health care providers and patient satisfaction and outcomes, such as promoting healing and reducing cost (Reiling and et al, 2008). According to WHO, OECD and WB, (2018), the availability of well-equipped facilities and the density of both hospitals and clinics is important, to attain accessible quality of care.

### 2.2.8 Devices and other technologies

The access to safe and effective medicines, devices and technologies, is abasic requirement for effective health care services. Medical equipment needs maintenance, staff training, and backup support. Medical equipment requires maintenance, user training, and backup support. In case spare parts are unavailable or in case shortage of consumables and personnel training, this equipment may be useless or unsafe (WHO, OECD and WB, 2018).

‘Medical device’ is any machine, tool, device, substance, reagent, software or other similar, that is used for one or more of the medical aims of diagnosis, prevention,

monitoring, treatment or mitigation of disease, investigation, amendment, maintaining life, medical devices disinfection and providing information through laboratory examination of samples taken from the human body (Global Harmonization Task Force, 2012). In addition to insufficient number of diagnostic facilities, health system-related obstacles in conducting diagnostic process are, the shortage of specialists at referral facilities, lack of finance for further diagnostic tests, deficiencies of laboratory services, limited access to telecommunication and lack of institutional support (Huaynate & et al, 2015). Childhood cancer are diagnosed through laboratory and imaging modalities

**- Laboratory modalities**

**A- Fluorescence in situ hybridization (FISH)**

A FISH is a test that "maps" the genetic material in human cells. A FISH test is useful in diagnosing some types of the cancer due to it can identify genetic abnormalities related to cancer (Ansorge,2019). A FISH test may also provide additional information when the type of cancer has been previously diagnosed, to assist predict a patient's outcome and if they are likely to respond to chemotherapy. A FISH test can detect genetic abnormalities in leukemias. (Ibid).

**B- Flow cytometry**

Now, many applications for flow cytometry can be applied to the study of cancer, including the identifying of aneuploidy in the DNA of cancer cells, immunophenotyping of leukemias and analysis of cancer cell proliferation (Orafo & et al, 1995). Flow cytometry is increasingly being recognized as a valuable diagnostic tool algorithm. This is particularly in the case in hematology and oncology disorders such as acute leukemia. Flow cytometry also shows its affect in grading and predictions of various disorders, DNA ploidy and minimal residue screening for disease is prime examples of this. Flow cytometry is also used for proper diagnosis and classification of tissue samples and many non-hematopoietic malignancies. The use of flow Cytometry in combination with other adjunct methods such as Molecular and cytogenetic studies ensure an accurate diagnostic and prediction realm (Handoo & Dadu, 2018).

**C- Minimal residual disease (MRD)**

MRD is a measure of the number of cancer cells remaining in a patient during or after chemotherapy or stem cell transplant and is a strong indicator of whether a patient's health is likely to relapse (Shaw, 2020), as it is an independent indicator of relapse risk in children with leukemia and is widely used for risk-adapted treatment (Athale & et al, 2016).

**- Imaging modalities**

**A - Computerized tomography (CT):**

CT is an extremely powerful imaging method, providing very valuable information, for the diagnosis, staging, and management of solid tumors in children (Granata & Magnano, 2013). In recent years, the concern of potential risks related with ionizing radiation from diagnostic imaging particularly from CT – has increased dramatically (Ibid). According to Eid (2019) study conducted in Gaza, there are 0.7 CT devices per 100,000.

**B - Magnetic Resonance Imaging (MRI):**

MRI has an elevated main role in the imaging of children with cancer. MRI provide many advantages compared with CT, including enhanced contrast resolution and tissue characterization. Moreover, the deficiency of ionizing radiation allows to obtain of multiphase post-contrast imaging in addition to treatment monitoring and long-term surveillance imaging, without the potential negative effects of repeated radiation exposure (Smith & Dillman, 2016).

MRI is able to provide entire body coverage, high tissue contrast for differentiation and good spatial accuracy without the use of ionizing radiation. Furthermore, the main advantage of this method in the management of children is represented by its ability to obtain relevant morphological and functional information in a single examination (Guimarães & et al. 2017). According to Eid (2019) study conducted in Gaza there are 0.3 MRI devices per 100,000.

### 2.2.9 Standards/guidelines

Standard is important for community and organization with a basis for mutual understanding to facilitate communication, measurement, trade and manufacturing

(CENELEC, 2019). Explicit guidelines do improve clinical practice when introduced in the context of rigorous assessment, moreover, Practice guidelines have the potential to improve process of care and patient outcomes. However, their beneficial effects depend on successful implementation (Graham& Harrison, 2005).

According to Wiener and et al, (2015), a shortage of standardized psychosocial standards in pediatric cancer results in inconsistent access to behavioral healthcare for children with cancer and their families. According to (WHO, 2002a) The motivation to start a national cancer control program or improve the performance of an existing program can come from different sectors within the country or can be a joint effort with international organizations. In close cooperation with its Member States and other partners, WHO has developed international strategy for the prevention and control of non-communicable diseases in which cancer control appears as one of the main priorities. People involved in drafting and performing the strategy for the national cancer control program should be health professionals, cancer experts, health workforce, patients' groups, and and other sector representatives involved governmental and nongovernmental leaders in cancer field and should to work together closely to develop successful program (WHO, 2002a).

### 2.2.10 Essential medicines

According to (Escalante& WHO, n.d.), the major causes of mortality & morbidity in low-income countries can be treated effectively with essential medicines. In many low-income countries, the required essential medicines are often not available, not accessible or not affordable.

Essential medicines improve health and save lives when they are available, affordable, of guaranteed quality and used correctly.. Lack of access to essential medicines remains one of the most critical public health problems worldwide, by combining public and private health systems, nearly two-thirds of the world's population have a good access to medicines leaving one-thirds without regular access. The major obstacles for access to essential medicines are: medicine Financing, treatment costs and globalization (WHO, 2004).

According to WHO (2004), the fair access to essential medicines is conducted through four dimensions, affordable prices, sustainable financing, reliable health and supply system and rational selection and use of essential medicines. Affordable prices include equitable pricing and reduction or elimination of duties and taxes. Sustainable financing includes

increasing public funding for essential medicines and reduction of patient out pocket especially for poor. Rational selection and use of essential medicines by consumers are important due to no health system in the world offers access to all medicines so it is important to develop national treatment and national lists of essential medicines. Reliable health and supply system are defined as the aspects of health system strengthening, encompass procurement, supply of medicines and regulatory control and workforce (WHO, 2004).

### 2.2.11 Records/documentation

The records constitute an enduring account of a patient's illness, their clarity and accuracy are essential for effective communication between healthcare providers and patients. Moreover, the preservation of good medical records ensures that a patient's estimated needs are totally met. Nevertheless, it is common to find unread entries and missing data,, and there is often conflicting between entries by health care providers (Abdelrahaman& Abdelmageed, 2014). Medical records form main part of a patient management and it is important for the physician and medical institution to properly maintain the records of the patient for two important reasons. The first is that it helps in the appropriate assessment of the patient and and the planning of treatment protocol. Second is that the legal system depends mainly on on medical records in cases of medical negligence. Therefore, medical records must be correctly written and kept for the interest of the physician and his/her patient (Bali & et al, 2011). Medical records are the source of most studies of the medical care process, and the lack of sufficient records is not compatible with good quality (Donabedian, 2005).

In many times records have defects, incomplete information, suffer sometimes from untruthfulness or from difficulties of interpretation (Donabedian, 2003), so patient records are too inadequate to serve as a basis for evaluation (Donabedian, 2005).

### 2.2.12 Accessibility

The access has three dimensions: the first dimension is the physical accessibility which reflects the presence of suitable health services within reach of needed people, including reasonable working hours, an efficient appointment system and management of other services that permit the patients to get the needed services when they need them. The second reflects the patients' ability to pay for services without financial consequences and the third dimension is acceptability of services which reflects the desire of people to seek

services and it is considered low when patients believe services as ineffective or culturally unacceptable (Thiede, Akweongo & McIntyre, 2007). According to Majeed and et al, (2018). The delay in scheduling diagnostic tests and waiting time for radiation therapy leading to system delay.

Njuguna & et al. (2016) indicate that early diagnosis and start of treatment are core goals in cancer care. According to WHO, (2010), Journey of a patient from Gaza to obtain medical care that is not locally available is long and complicated beacause has three major steps, getting referred, obtain permit to cross Erez checkpoint and reach the hospital, each of them involves several smaller stages and decisions and the patient has little or no control and uncertainty of what the final outcome will be. Cancer treatment was the most common reason in November, 2016 for patients to be referred by the Ministry of Health for medical care abroad, as only 58.76% of application for permits submitted by cancer patients for travel in November were approved for travel in November (WHO, 2017c).

### 2.2.13 Waiting time/Appointment time

Trust in the care provider and perceived quality of care is inversely correlated with long waiting times (Bleustein and et al. 2014). Without proper scheduling, the clinic will quickly become a chaotic, unorganized mess. This elevates stress not only for your staff but also for clients (Appointment Plus, 2013), and shorter cancer waiting times can lead to earlier diagnosis, quicker treatment, reduced risk of complications, improved patient experience and improved cancer outcomes. (Nuffield Trust, 2021).

### 2.2.14 Treatment modalities

Treatment options for pediatric cancer depend on many factors, as the tumor type and stage, the patient's preferences, general health and possible side effects (American Society of Clinical Oncology, 2020a). The referral and system delays increased due to shortage of cancer facilities in the hospitals for cancer diagnosis and treatment (Majeed & et al. 2018).

There are several treatment ways for children with cancer represented by surgery, chemotherapy, immunotherapy, radiation and a bone marrow transplant.

- **Surgery**

Surgery is the extraction of entire tumor whether cancerous or noncancerous and the margin tissue around the tumor. Oncology surgeon responsible for treating the tumor by surgery (ASCO, 2020a). Many children with a tumor will need surgery at some point as a part of their treatment, and the possible side effects of surgery may depend on the tumor type, whether it has metastasized, location, and age of the child (Ibid).

- **Chemotherapy**

Chemotherapy is the use of drugs to destroy cancer cells, by preventing cancer cells from development and dividing (ASCO, 2020a). A chemotherapy schedule consists of a set number of cycles given over a set period of time. The possible side effects of chemotherapy depend on the individual and the drug and dose used, but they can include, nausea, vomiting, fatigue, diarrhea, infection risk, hair loss and lack of appetite (Ibid). Treatment late effects may occur because some types of chemotherapy drugs can destroy healthy cells and prevent them from growing and developing the way they should, affecting the growing of a child's whole body. (ACS, 2017).

- **Immunotherapy**

Immunotherapy is used to boost the body's natural defenses to fight the cancer. It uses substances made either by the body or in a laboratory to improve or restore the function of immune system (ASCO, 2020a). Immunotherapy includes cancer vaccines, monoclonal antibodies and interferons. Immunotherapies can cause different side effects as skin reactions, flu-like symptoms, weight changes and diarrhea (Ibid).

- **Radiation**

Radiation therapy is the use of high-energy x-rays or other particles such as photons to destroy cancer cells (ASCO, 2020a). A radiation oncologist is responsible for treating cancer by radiation therapy. There is external beam radiation which is radiation given from a machine outside the body and internal radiation therapy when radiation therapy is given using implants and new methods of radiation delivery have been developed in recent years. Possible side effects of radiation therapy may include mild skin reactions, fatigue, upset stomach, and loose bowel movements (Ibid). Radiation can influence on normal cells and

cancer cells (ACS, 2017). In Skaik (2013) study that was conducted at the oncology departments and out-patient daily care of the cancer clinics in three hospitals in the Gaza (Al-Shifa and European Gaza hospitals and RSPH), 5.8% of the patients received radiotherapy abroad due to absence of radiotherapy in Gaza.

- **A bone marrow transplant**

A bone marrow transplant is a medical procedure in which cancer-containing bone marrow is replaced with highly specialized cells called hematopoietic stem cells grow into healthy bone marrow. Hematopoietic stem cells are blood-forming cells found both in the bloodstream and in the bone marrow (ASCO, 2020a). A bone marrow transplant is also called a stem cell transplant because the stem cells in the blood that are typically being transplanted, not the actual bone marrow tissue (Ibid).

### 2.2.15 User-provider interaction

The professionals need to evaluate each service user's needs and consider how these can be met. Relational continuity is needed to preserve the service user's challenges and goals throughout the services and to improve health behavior changes (Sagsveen and et al, 2019). Providers must ensure that they provide pediatric cancer services with ensuring the dignity and respect of people at all times. The aim of the regulation 10 on dignity and respect is to ensure that people using the service are treated with respect and dignity at all times while they are receiving care and treatment. This can be done by guarantee people's privacy and treating them equally and providing any support they may need to be independent and involved in their community (Care Quality Commission, 2014).

### 2.2.16 Coordination

Strengthening coordination between nurses and other providers is fundamental to improve patient care quality (Havens & et al. 2010).

Frequently, the coordination of chronic patient care involves moving between primary care and surgical specialists and different care settings. Surgical patients and their caregivers frequently feel weak during these moves and require care coordination processes including information infrastructure, confidence, patient health education, and information sharing between health care providers (Brooke & et al. 2018).

### 2.2.17 Follow up

Most side effects of childhood cancer treatment appear during or after treatment and disappear after a short time. But some problems might not go away until months or years after treatment. These problems are called late effects and the ongoing follow-up after cancer treatment assists the doctors to treat these effects as quickly as possible (ACS, 2017). The aim of follow up care is to check the cancer has not returned, manage any side effects and monitor overall child health. The child's follow-up care may include regular physical examinations, medical tests, or both. All children treated for cancer should receive lifelong follow-up care. (ASCO, 2020b).

Because of long term consequences associated with pediatric cancer treatment, systematic continuous follow-up of these patients is important to provide early detection of and treatment for potentially serious late effects. Moreover, health counseling and improving of healthy lifestyles are important aspects of long-term follow-up care to enhance risk decreasing of health problems that typically appear during adulthood (Bhatia & et al. 2009).

### 2.2.18 Number of patients accessed and/or received cancer services

The numbers of children with cancer are important, but it has meaning if they take into account patient categorization which assist to identify various types of patients or health care products and to estimate differences in complexity allowing many useful comparisons of costs in relation to outputs (Quentin and et al, 2016).

### 2.2.19 Patient satisfaction

Patient satisfaction is a measure of patient satisfaction degree with the provided health care from their health care provider.. Patient and parent satisfaction are the main important aspect of ensuring quality that includes all aspects from medical to psychosocial issues during the illness pathway. Such insights are valuable for improving health care to ensure that children with cancer and their families are optimally supported and optimally directed during the hard time they face when receiving the diagnosis and undergoing treatment (Wangmo & et al, 2016)**.** Patient satisfaction is one of the most important factors that indicate the success of a health care facility (Manzoor & et al, 2019). Only Patient satisfaction, which is an indirect indicator of the quality of doctor or hospital performance

(Prakash, 2010). There are major causes for dissatisfaction, shortag of drugs and supplies, poor information provision, long waiting time, poor cleanliness, lack of privacy and insufficient visiting hours (Assefa, Mosse & Hailemichael, 2011). The most important factors have impact on patient satisfaction are medical staff's service attitude, medical staff services technology and hospital convenience (Fang, Liu and Fang, 2019).

### 2.2.20 Quality of care

Quality of care is the degree to which health services provided to individuals and populations increase the likelihood of needed health outcomes and are consistent with effectiveness, safety, people centeredness, equity, timeliness, efficiency and integration of care (WHO, OECD& WB, 2018). There are many factors such as resources availability, collaboration among patients and cooperation among providers influence the services quality and patient outcomes, also supportive leadership, suitable planning, education and training, effective management of resources and processes promote medical services quality (Mossadeghrad, 2014). In addition, multi-disciplinary teams working at primary, secondary and tertiary are important to the delivery of high-quality cancer care and treatment decision-making is a key function. (Blazeby & et al. 2006).

A study was conducted by Anan (2011) presented the three major factors identified by the patient that indicate to good quality of care is the availability of drugs (67.3%), followed by respectful interactions with health care provider (46.5%), then treatment of the disease (34.5%).

### 2.2.21 Client's needs and perspectives

The beneficiaries of health care services assess their quality in relation to the extent to which their needs and expectations are met, while health providers focus on technical performance and adherence to standards. Moreover, linking between receivers and providers thoughts about quality of health services would increase the likelihood of the desired health outcomes on individuals and populations (WHO, 2000). Often, encouraging feedback from parents of children with cancer will enable setting of priorities for quality improvement (Keiza, Chege &Omuga, 2017). improvement in developing countries health care delivery can succeed if the opinions and inputs of consumers of health services are integrated into health care delivery, so Healthcare providers should consider client satisfaction as a key component strategy (Ogbordjor, Gabla& Mensah, 2019). the study

was conducted by Zebiene & et. al. (2004) showed that meeting people's expectations increased their satisfaction and satisfaction of clients is an important indicator for the success of health services and this study found that the most important expectations for patients were good understanding and informative explanation of their condition.

### 2.2.22 Quality of life

Quality of life (QOL) describes the level of physical, emotional and psychological well-being that an individual experiences. The influence of cancer and its treatment on the developing body, brain and mind can significantly reduce QOL, affecting treatment decisions and supportive care and long-term follow-up (Dimaras & et al, 2015). Higher frequency of hospital visits, male sex, longer diagnostic and treatment duration, and increased treatment intensity are all related to more morbidity and injury, great concern, anxiety and nausea which reflect a poor quality of life in pediatric cancer patients (Hegazy & et al. 2019).

Palliative care is an approach dedicated to improve the QOL of patients with the life-threatening diseases, and improve QOL of their families by alleviating suffering through the early identification, correct evaluation and treatment of pain whether physical, psychosocial or spiritual (WHO, 2018).

According to Abu Hamad, Skaik, Abu Odah, (2016), palliative care services should be linked to cancer treatment strategies in order to make the optimum use of scarce resources and this study showed that currently, there are no well-defined palliative care services. However, some components related to palliative care services are available and offered within general oncology services. Also, there is no home visit program for patients who are unable to come to the clinic and the oncology staff does not provide home services. Nayak & et al. (2017) indicate cancer symptoms management including pain is a critical issue in the care of patients with cancer and the study indicates that all health professionals must ensure that patients receive appropriate and timely education and care. Nurses have the power impact a patient's life. Nursing provides an empathetic ear, educational information, medical management and psychological support to improve QOL for all patients (Kirsten, 2012).

Global data indicates that healthcare for children with cancer should include psychological services to prevent long-term emotional and behavioral problems and these services must be provided in an age-suitable, developmentally appropriate, and time-sensitive manner (Marcus, 2012). A study conducted by Rahimi & et al, (2014) to determine relevant factors to QOL among preschool children with cancer revealed the total mean score of QOL is 62.96%. According to Afifi & et al. 2020 study, in Gaza, children with thalassemia had the lowest quality of life (70%), followed by children undergoing hemodialysis (63.3%) then the children with cancer (58%) using Peds QL 4.0 generic core scale.

### 2.2.23 Influencing factors

Delays in the diagnosis of childhood cancer were most affected by the child's age, parental education, family's socioeconomic status, cancer type, and site of cancer (Abdelkhalek & et al. 2014). Patients may think cancer is untreatable or think cancer treatment can leading to morbidity or mortality, resulting in delaying of care. And the morbidity of cancer treatment may create concerns of alienation from a person's family or community (WHO, 2017b). The disease-specific variables, type of cancer, extent of disease, and time left to live are strongly affect pain (Ruston & et al. 2003).

In Salah, Abu Reyala & Al Jerjawy (2018) study, the familial levels of income and the number of family members influence the quality of life of children with cancer as there is statistically significant difference in the QOL among children according to different their families' level of income and there is statistically significant difference in the QOL among children between their different number of family members as scheffe test showed there is difference between those who have family members <4 and those who have family members >8 in favor of those have family members <4 . The gender, age of the child and diagnosis years don't influence the quality of life of children with cancer as there is no statistically significant difference in the QOL between male and female children in the Gaza, there is no statistically significant difference in the QOL between different age groups of children and there is no statistically significant difference in the QOL among children according to their different diagnosis years.

# Chapter Three

## Methodology

This chapter illustrates the information about the methods used to conduct this study. Including the study design, study population, study setting, study period, study sampling, study instruments, data collection procedures, data entry and analysis, validity and reliability of instruments, pilot study, limitation of the study and ethical considerations.

### 3.1 Study design

The design of this study is triangulated, cross sectional mixing quantitative and qualitative approaches. It is used to describe the extent of services provision to achieve pediatric cancer management. The aim of triangulation in this study to increase findings, as it is experiment to illustrate richer and complex human behavior by studying it from more than one point (Cohen and et al, 2000). Cross sectional design reflects the existing facts at the same point of time of data collection, it consumes less time than other longitudinal studies. Methodological triangulation would provide combination between quantitative (Interviewed questionnaire with caregivers of patients) and qualitative (in depth interviews).

### 3.2 Study population

#### 3.2.1 Quantitative study population

- Regarding the quantitative part, the study population consisted of 210 children diagnosed with cancer who received services at RSPH in six months interval, from January to June (Maximum interval for internal follow up)
- The active files for the same number of children above who were diagnosed with cancer and received services at RSPH in six months interval, from January to June.

#### 3.2.2 Qualitative study population

- Regarding the qualitative study the interviews were conducted with 12 key informants, 5 of them are policy makers who are involved in pediatric cancer management at the national level and 7 staff engaged in provision of pediatric cancer services at RSPH

### 3.3 Study setting

RSPH is the main pediatric cancer services provider in the Gaza Strip.

### 3.4 Study period

The study consumed approximately 1 year, it has started in January and was completed by October, 2021

### 3.5 Eligibility criteria

#### 3.5.1 Inclusion criteria

- Children diagnosed with cancer and receiving treatment at RSPH in six months interval, from January to June (Maximum interval for internal follow up).
- Children diagnosed with cancer aged 0-12 years.
- All active files for the children diagnosed with cancer who received pediatric cancer care in six months interval from January to June (Maximum interval for internal follow up).

#### 3.5.2 Exclusion criteria

Children diagnosed with cancer who don't meet the inclusion criteria.

### 3.6 Study participants

#### 3.6.1 Quantitative data (Census study)

- the researcher reached to all children diagnosed with cancer who received services in RSPH in the six months interval (210) to conduct interviewed questionnaires with their caregivers (Census study).
- Records check of the active files for the same number of children above who were diagnosed with cancer and received services at RSPH.

### 3.6.2 Sampling for qualitative data

- **Selection of Key informants (Policy makers and staff for interviews)**

The selection of the Policy makers for depth interview was non- random purposive sample, which is based on selection of people who are engaged in pediatric cancer management. The selection of key informants was through writing a list of the key informants who have knowledge and are responsible on pediatric cancer management.

- A non-probability purposive sample for staff working in pediatric hematology & oncology department at RSPH for in-depth interviews.

## 3.7 Study tools

This study used different tools, which are presented in the following summary table 3.1. It explains the study tools of both quantitative and qualitative parts with numbers and focus.

**Table (3.1): Study tools**

| Participant-subject | Method | Number | Focus |
|---|---|---|---|
| Caregivers of children with cancer | Interviewed structured questionnaire with caregivers of children diagnosed with cancer who received services in six months interval, from January to June. | 210 | The main items for the questionnaire:<br>- General information<br>- Socio-demographic and economic variables of patients<br>-Medical information on cancer<br>- Coordination<br>- Access status and waiting time.<br>- Patient-provider interaction<br>- Satisfaction on services<br>- Quality of care<br>- QOL by using SDQ which involves emotional, conduct, hyperactivity, peer and prosocial domains.<br>- Client perspectives about cancer services |
| Medical records | Emblemhealth (2012) model, Pediatric and Adolescence Medical Record Review Tool-Primary Care Provider, for the evaluating of medical files with modifications to suit the study (Annex3). | 210 | The researcher checked the records documentation, demographic data, diagnosis, medication records, chemotherapy request and the type and stage of cancer, the number of patients served and checked all services provided to children patients with cancer. |

***Table (3.1a): Continued***

| | | | |
|---|---|---|---|
| Facility | Observation | | -The researcher observed the:<br>The facility accessibility info (geographical coverage, location, criteria for admission)<br>Infrastructure (space, power source, water, location.<br>Available equipment /tools<br>Technology for data base information) |
| Policy makers | Key informant interviews (A semi-structured schedule with open-ended questions was used) | 5 | The interviews included responsible key informants in MOH, RSPH, treatment abroad, donor community, Information system and cancer registry<br>-The areas of interest concentrated on the following items;<br>- The strategy planning for cancer control.<br>- Information system / Reporting<br>- Standard and protocol.<br>Monitoring & evaluation -<br>- Quality of care<br>- Accessibility and Referral system<br>- Facility capacity to respond to needs of patients,<br>- Human resources (number, distribution, qualifications, sex and age)<br>- Diagnostic equipment and physical Space of facilities.<br>Limitation - |
| Staff who are working at RSPH. | Key informant interviews (A semi-structured schedule with open-ended questions was used) | 7 | -The researcher conducted interviews with staff who are working at RSPH. The main items of interviews included<br>- Protocols<br>- Quality of care<br>-Their knowledge, experiences-<br>- Training<br>- Coordination<br>- limitation in the provision of services |

### 3.8 Ethical consideration

is represented by:

- Academic approval from the School of Public Health at Al-Quds University before starting the thesis.
- Research ethical approval from Helsinki committee as shown in Annex (1)
- Approval letters were sent to the general director of the RSPH
- Approval from director of RSPH
- To guarantee participation rights, all participants received enough information about the goals of requested study topic and the procedure of data collection to encourage their participation, with ensuring of their privacy and confidentiality.
- The key informants and staff have been asked for their approval to record in-depth interviews

### 3.9 Data collection

#### 3.9.1 Quantitative data

The researcher and three data collectors conducted interviewed questionnaires with 210 caregivers of pediatric cancer who received services in RSPH in six months interval. The data collectors were trained on interviewing steps to standardize the data collection method and the filling of questionnaire took 60 minutes.

The researcher checked the active files of 210 children diagnosed with cancer at RSPH by using selected study checklist

#### 3.9.2 Qualitative data

The second component of the data collection was 12 KIIs (Policy makers & staff). Interviews were conducted after the initial findings of quantitative data. The data gathered from key informative person's interviews at the place preferred by key informant after explaining the aim of interview and taking their consent to participate in the interview, the intended uses of the information and confidentiality guarantees were provided and the interview conducting took approximately 60 minutes. The interview was started with factual questions followed by questions requiring their opinions, the data was collected through audio recording, note was taken and the transcript is done immediately after the meeting to ensure accuracy (USAID, 2011).

## 3.10 Scientific rigor

### 3.10.1 Quantitative approach

In quantitative data rigor can be achieved by measurement of the validity and reliability. Validity is the ability of measuring tool to really measures what is intended to measure (Middleton, 2019). The questionnaire and checklist were evaluated by experts to assess their suitability to ensure the tools items cover the topic and their comments were taken into account. A pilot study was conducted before the actual data collection to examine the response of caregivers of children patients with cancer to the questionnaire and how they understand it.

Reliability: Reliability is consistency of results by using the same methods under stable conditions (Middleton,2019).

The following steps are done to assure instruments reliability

- The data collectors trained on interviewing steps to standardize the data collection method.
- The data entry is done in the same day of data collection, which allowed to check the data quality, to re-fill the questionnaire when required.
- Data reviewing if being missed or inconsistent before analysis.
- Re-entry of 5% data after finishing data entry is done to assure accuracy of its entry.
- Each domain was individually assessed using Cronbach's alpha as table 3.2 shows:

**Table (3.2): Cronbach's alpha coefficient**

| | **Items** | **Cronbach's Alpha** |
|---|---|---|
| 1. | Section 5: Patient -provider interaction | 0.921 |
| 2. | Section 7: Satisfaction | 0.835 |
| 3 | SDQ | 0.701 |
| 3.1 | Emotional | 0.704 |
| 3.2 | Conduct | 0.701 |
| 3.3 | Hyperactive | 0.607 |
| 3.4 | Peer | 0.641 |
| 3.5 | Pre social | 0.700 |

### 3.10.2 Qualitative approach

A Peer check: experts revise the questions of the interviews to assure that they cover all the required dimensions of the topic.

B Audit trial: the researcher kept all records of taps, transcript for the key informant interviews and for tracking the information by other at any time.

C Pilot key informant & staff interviews, the researcher did a pilot trial for key informants to ensure the relevance of the questions and to measure the time required for the key informant interviews.

D Member check: informant feedback to ensure validity and accuracy of the transcripts during the interviews.

E Prolonged engagement: in this method the researcher asked some of questions in different ways to ensure that the participants understand the meaning of questions for the most appropriate answer to the questions asked, covering all interview dimensions properly and adequate immersion by hearing the records at least three times.

F Data entry is conducted in the same time of data collection.

## 3.11 Pilot study

Pilot study is done before starting data collection to detect the appropriateness of the study tools, train researcher for data collection and improve validity and reliability of the study through taking consultations from experts before data collection to evaluate the questionnaire and questions of key informant interviews. pilot questionnaire, pilot key informant interviews are conducted to ensure the suitability of the questions and to measure the required time for the interviews.

## 3.12 Data analysis

### 3.12.1 Quantitative data analysis

During data collection, the researcher revised the questionnaires continuously as well as before entering them to ensure validity of information. The researcher used the statistical Package for Social Sciences version 25 for data coding, entry and analysis, then followed by examining collected data from missing data, then entering the data. Re-entry test was

performed with 5% of the data, data cleaning was conducted to check illogical values, then the processing of this data was conducted. Frequency tables were done to show sample characteristics and plot differences between various patients' characteristics variables. Descriptive statistics to analyze numerical data which helps to describe, or summarize data in a meaningful manner and it helps in calculation of central tendency of mean, median and mode. Moreover, cross tabulation for main findings and advanced statistical tests were done when required to analyze questionnaire data, such T-test to examine the relationship between dependent variable and two categories as between total difficulties among children and gender and One-way ANOVA test to investigate the relationship between dependent variable and more than two categories as between total difficulties among children and father's work.

### 3.12.2 Qualitative data analysis

Open coding thematic analysis method used to analyze the transcripts of key informant and staff interviews. The researcher started by obtained the main findings from the transcripts of staff and key informant interviews, deep reading of raw data extracted from the transcripts. The notes were taken to identify the important items. The researcher then started with the open coding thematic analysis method through the categorization of related ideas, then comparisons between the quantitative and the qualitative findings were applied to provide rich items for further discussion.

## 3.13 Limitations of study

- Limited local paediatric cancer information and oncology studies in the Gaza strip.
- Files may have missed sheets and have less accurate data.
- The study not consider the children patients with cancer who don't come to the RSPH.
- The study includes only the children with cancer who have received services in six months interval.

# Chapter Four

## Results and Discussion

### 4.1 Introduction

This chapter illustrates the results of quantitative and qualitative data that were conducted to evaluate pediatric cancer services provided in the Gaza Strip according toDonabedian model that shows demographic, economic & health related characteristics of children diagnosed with cancer, input/structure of pediatric cancer service (Workforce, information system, physical space and facilities, devices & other technologies, Guideline/standard and essential medicines), process (Documentation, accessibility, waiting time, treatment modalities, user provider interaction, coordination and follow up) and outcome (No of patients accessed and/or received cancer services, Sessions, activities, satisfaction, quality of care, client perspective and quality of life). It begins with a descriptive analysis as the descriptive tables show the results compiled from the total respondents (210) and show the results compiled from the medical records. Moreover, this chapter presents the main inferential analysis which highlights variances of satisfaction about provided services, user provider interaction and strengths and difficulties amongst children with cancer. Verification was done through key informant interviews with intentionally selected individuals who are engaged in pediatric cancer management.

### 4.2 Descriptive analysis

#### 4.2.1 Socio-demographic and economic characteristics

RSPH is the main pediatric cancer care provider in the Gaza strip, it provides services to children with cancer from the North to the south governorates. Study participants from Gaza governorate were the highest percentage 44.8%, while participants from the Rafah and mid zone governorates were the lowest (10.5%) as illustrated in Figure 4.1. Variations in the place of residence of the general population and distribution of the cases may be related to documentation gaps, differences in reporting cases or other reasons that require further investigations.

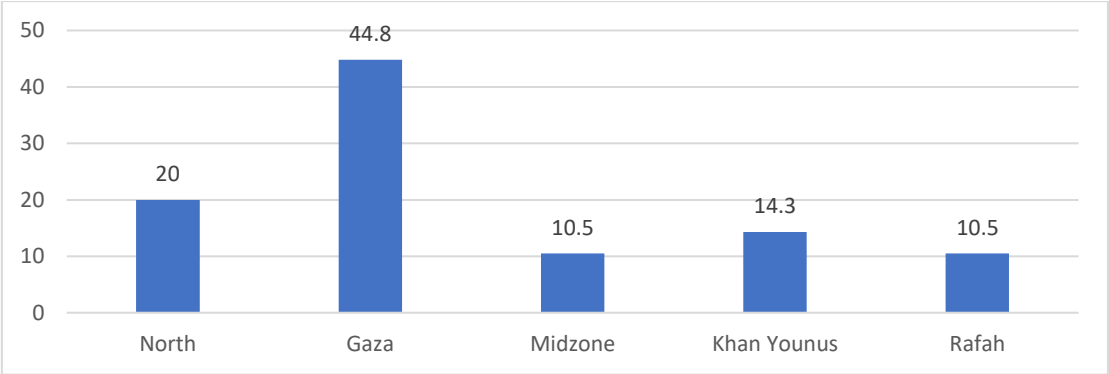


**Figure (4.1): Distribution of children with cancer according to governorates**

**Table (4.1) Distribution of the children diagnosed with cancer by demographic related data**

| Items | N | % |
|---|---|---|
| **The respondent's relationship with the child** | | |
| Parents | 198 | 94.3 |
| From Family (grandmother, Grandfather, Aunt, Sister, Uncle) | 12 | 5.7 |
| **Gender of the child** | | |
| Male | 111 | 52.9 |
| Female | 99 | 47.1 |
| **Total** | **210** | **100.0** |
| **Governorates** | | |
| North | 42 | 20.0 |
| Gaza | 94 | 44.8 |
| Midzone | 22 | 10.5 |
| Khan Younus | 30 | 14.3 |
| Rafah | 22 | 10.5 |
| **Total** | **210** | **100.0** |
| **Age of the child** | | |
| Less than 5 Years | 64 | 30.5 |
| From 5 to 9 Years | 94 | 44.8 |
| More than 9 | 52 | 24.8 |
| **Total** | **210** | **100.0** |
| **Mean = 6.70, Md = 7.00, Std = 3.13** | | |
| **Father working status** | | |
| Working | 111 | 52.9 |
| Not Working | 95 | 45.2 |
| Retired | 4 | 1.9 |
| **Total** | **210** | **100.0** |
| **Mother working status** | | |
| Working | 13 | 6.2 |
| Not Working | 197 | 93.8 |
| **Total** | **210** | **100.0** |
| **Income (ISH)** | | |
| No income | 70 | 33.33 |
| Up to 999 | 68 | 32.4 |
| 1000 to 1999 | 57 | 27.41 |

***Table (4.1a): Continued***

| | | |
|---|---|---|
| 2000 or more | 15 | 7.1 |
| **Total** | **210** | **100.0** |
| **Mean = 1010.79, MD = 1000.0, Std = 774.76** | | |
| **Receiving social assistance** | | |
| Yes | 70 | 33.3 |
| No | 140 | 66.7 |
| **Total** | 210 | 100.0 |
| **Source of assistance** | | |
| Government | 29 | 42.6 |
| UNRWA | 28 | 41.2 |
| Qatar | 6 | 8.8 |
| Other (CHF, Basmat Amal) | 5 | 7.4 |
| **Total** | **68** | **100.0** |

As shown in Table 4.1, the percentage of males (52.9%) is higher than females (47.1%), it is consistent with Salah, Abu Reyala & Al Jerjawy (2019) study, in which the male was (55.5%) and the females (44.5%). During 2015-2016, in the Gaza Strip, the pediatric cancer cases under 18 years were 210, 119 were males with 57% and 91 were females with 43% (MOH, 2016) According to Williams & et al. (2019), that most types of cancer are directly proportional to the male sex and the high incidence rates in males remained steady during childhood period, this indicates that childhood hormonal may not be the primary driver for the gender disparities in childhood cancer so the observed disparities may be due to gender differences in exposures, genetics, or immune responses. (Williams and et al, 2019).

As shown in Table 4.1, the breakdown employment status by gender shows that 52.9% of men, fathers of children with cancer were employed at the time of data collection compared to 6.2% of children's mothers. The results are inconsistent with the findings of PCBs, in which the unemployment rate in last quarter in 2020 is about 43%, 38.7% among men and 60.4% among females (PCBs, 2021b). The findings have revealed that the monthly income for children with cancer families was 1010.79 NIS with SD (774.76). It is noticeable that 33.3% of patient caregivers reported didn't having income, this may does not reflect the reality: some children's caregivers did not provide factual data in reference to this question.

The poverty line and the deep poverty line for reference household consisted of 2 adults and 3 children) were 2,470 NIS, and 1,974 NIS, respectively (PCBs, 2017). As noticeable in figure (4.2) that only 7.1% of families in this study have average monthly income above the poverty line and 92.9% of families have a monthly income below the deep poverty line

or below the poverty line. the results are incompatible with the findings of PCBs (2017), which state that 53% of individuals in Gaza Strip live below deep poverty or poverty line. This result reflects deterioration of economic situation in Gaza, which increases the challenges of the burdens of access to services and transportation burdens on people.

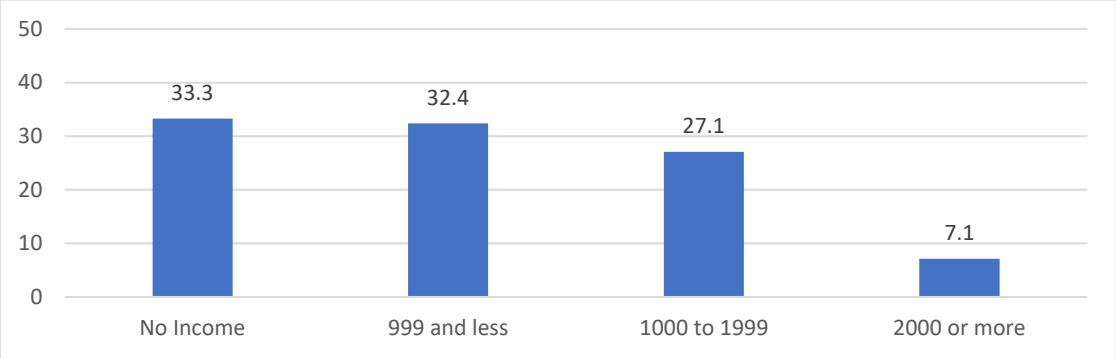


**Figure (4.2): Distribution of participants according to income**

### 4.2.2 Medical history

#### 4.2.2.1 Reason for today's visit

As shown in Table 4.2, about 70.5% of participants indicated that the main reason of their visit with their children to RSPH was to conduct the laboratory tests for their children, followed by performing follow up with 69%, only 10.5% reported the reason of their visit was to conduct medical imaging tests and 3% reported that their visit was an unscheduled visit. This result might reflect awareness of caregivers about the importance of conducting laboratory tests and follow up regularly and the hospital's interest in alerting patients for continuous follow-up.

#### 4.2.2.2 Cancer type

The percentage of Leukemia represented 52.38% among all cancer types in children as shown in Table 4.2, this may indicate to the high incidence rate of leukemia among all cancer types in children followed by lymphoma with 11.43% then Wilms tumor with 10.95% then neuroblastoma and brain, as each of them represent 7.14%. When comparing the results collected from participants with the types recorded in the medical record, the leukemia in medical records represented (48.57%, n=102), lymphoma (11.9%, n=25), Wilms ' tumor (10.95%, n=23), neuroblastoma (7.62%, n=16), Brain (7.14%, 15), (Bone 4.76%, n=10), rhabdomyosarcoma (3.34%, n=7) and germ tumor (2.86%, n=6). These differences may indicate that there is shortage in the information that transmitted from the medical

staff to patients or the child's caregiver doesn't know the exact classification of the disease. According to MOH (2021), in 2016- 2020, the most common types of pediatric cancer were as the following, leukemia which represented the first type with 26.7%, while Brain cancer was the second type with 17.7% of all pediatric cancers, Bone cancer represented 16.2%, Lymphoma with 11%, and neuroblastoma with 4.1% of all pediatric cancer types (Annex 8). This finding was also supported by KIIs as a nurse noted *"In the last years we noticed an increase in the number of Wilms' tumor cases, as the number of Wilms ' tumor cases didn't exceed 3 or 4 cases between 2008-2011 years, and we noticed a relapse in nearly half of neuroblastoma cases* "The surgeon added his comment " *In the past year we have performed nearly ten surgeries for Wilms ' tumor cases"*

**Table (4.2) Distribution of the children diagnosed with cancer according to their medical history**

| **Items** | **N** | **%** |
|---|---|---|
| **The reason of your today's visit to the hospital** | | |
| To do laboratory tests | 148 | 70.5 |
| Scheduled appointed-follow up | 145 | 69.0 |
| To take a chemotherapy dose | 53 | 25.2 |
| To do medical imaging tests | 22 | 10.5 |
| Walk-ins-visit | 8 | 3.8 |
| **Type of cancer** | | |
| Leukemia | 110 | 52.38 |
| Lymphoma | 24 | 11.43 |
| Wilm's tumor | 23 | 10.95 |
| Brain | 15 | 7.14 |
| Neuroblastoma | 15 | 7.14 |
| Bone | 10 | 4.76 |
| Germ | 5 | 2.38 |
| Rhabdomyosarcoma | 4 | 1.9 |
| Other | 4 | 1.9 |
| **Total** | **210** | **100.0** |
| **Disease degree at diagnosis as reported by respondents** | | |
| Low | 30 | 14.28 |
| Intermediate | 38 | 18.1 |
| High | 69 | 32.86 |
| I don't know | 73 | 34.76 |
| **Total** | **210** | **100.0** |
| **Interval since the diagnosis** | | |
| 12 months and less | 84 | 40.0 |
| From 13 to 36 | 69 | 32.9 |
| 37 and more | 57 | 27.1 |
| **Total** | **210** | **100.0** |
| **Mean = 29.35, MD= 19.5, Std= 27.6** | | |
| **Having other chronic diseases- co- morbidities** | | |
| Yes( paralysis, Cardiac, brain atrophy) | 15 | 7.1 |
| No | 195 | 92.9 |
| **Total** | **210** | **100.0** |

#### 4.2.2.3 Duration of disease

As shown in table 4.2, many children with cancer (40%) were diagnosed in the past 12 months. Children newly diagnosed with cancer need more follow up and treatment while the older children need only follow up.

#### 4.2.2.4 Disease degree/severity

Concerning the degree of disease, 14.28% caregivers described it as a low grade, 18.1% of caregivers described it as intermediate degree, 32.86.% reported that their children had been diagnosed with high drgree cancer, while 34.76% of participants don't know the degree. Their lack of knowledge the degree of the disease degree may indicate to not having enough information transferred from the medical staff to patient's caregivers or their children have type of cancer with no degree as acute leukemia.

#### 4.2.2.5 Co-morbidities

About 7.1% of children with cancer have co-morbidities along with cancer, this requires caring for them and providing a comprehensive service to these people.

#### 4.2.2.6 Receiving services from other service providers

Chemotherapy is still the major treatment method to manage cancer within the period of data collection. As shown in table (4.5) later, 84.3% of children with cancer received pediatric cancer services at more than one location: local hospitals in Gaza and abroad. when the service is not available locally, MOH refers their patients abroad especially due to lacking of specialized services such as radiotherapy, chemotherapy, surgery, bone marrow transplantation and diagnostic tests and for other reasons. As 47.5% of children with cancer receive services in Jerusalem followed by 40.1% of them receive services in West bank then 13.6% in occupied Palestine 48. This referral costs money for MOH and patient's caregivers and it causes exhaustion to patient and patient's caregiver. In addition to political challenges represented by denial permits and investigation at the crossings.

**Table (4.3) Distribution of the children diagnosed with cancer according services they are received**

| Items | N | % |
|---|---|---|
| **The services that the child receives from RSPH** | | |
| Lab tests | 209 | 99.5 |
| Follow-up | 208 | 99.0 |
| Counseling | 181 | 86.2 |
| Chemotherapy | 159 | 75.7 |
| Medication dispensing | 151 | 71.9 |
| Medical imaging tests | 150 | 71.4 |
| Psychological support | 123 | 58.6 |
| **In the RSPH the child receives psychosocial services** | | |
| Yes | 123 | 58.6 |
| No | 83 | 39.5 |
| I don't know | 4 | 1.9 |
| **Total** | **210** | **100.0** |
| **Your main source of information about children cancer is from** | | |
| Physician | 202 | 96.2 |
| Internet | 44 | 21.0 |
| Friend | 14 | 6.7 |
| Family | 9 | 4.3 |
| Other | 2 | 1.0 |

- **Psychological services**

The most common side effects of chemotherapy are fatigue, nausea, vomiting, dry mouth, changes in savor, alopecia and constipation (Altun & Sonkaya, 2018) and despite advances in treating many of the side effects related with chemotherapy, alopecia is still a difficult problem to solve, which lead to psychosocial and quality-of-life consequences (Hesketh & et al. 2004), therefore psychosocial support is considered essential for cancer patients. As shown in table 4.3, 58.6% of children diagnosed with cancer received psychological support in RSPH from psychological support team affiliated with the PCRF. This is an important part of palliative care services. But even so, the nurse in pediatric cancer department said '*There is no psychologist in pediatric oncology department from MOH but there is psychological support team affiliated with the PCRF and their support is not enough and is not continuous*'.

A key informant confirmed the above as she said '*The psychological support for children with cancer is supposed to be in their homes and there should be support for their families to achieve the continuity of treatment due to their families suffer a lot because of their children's illness'.* But a psychologist in the psychological support team in hematology and oncology department affiliated with the PCRF said that '*We reached children in their homes, but because of the Corona virus pandemic, our visits to homes of children with cancer decreased, in addition that, we work under contracts to work for nine months a year and the last three months of every year we don't work, and this affects the continuation of the service to support children with cancer psychologically*'.

The other nurse added '*Psychological support team told them before the Corona virus pandemic, there are cases don't accept the psychological support team visits to their homes". The head of nursing department added that "we as nurses try to support the children psychologically*'.

- **Health education**

Despite the 96.2% of participants as shown in table 4.3, reported the main source of information about pediatric cancer from doctors and 21% reported the source of information from internet. A nurse said '*Our patients may not receive the enough required health information due to short contact time with doctor and the increase in the number of cases are seen daily, I heard one caregiver for a child with cancer advising the other caregiver not to feed her child fruits and vegetables with their peel during chemotherapy period as the doctor at Hadassah hospital told her'.*

The most important health information as perceived by the majority of cancer patients (67.26%) relates to information on the specific type of cancer, followed by chemotherapy side effects and their management (63.29%) then "prognosis (survival)" (51.8%). Doctors were the main source of information on cancer (88.8%), followed by nurses (34%). Periodic assessment of cancer patient information requirements is also critical (Mekuria & et al. 2016).

**Table (4.4) The unavailable services at RSPH as perceived by participants**

| **The health services that are needed for the child patient with cancer always available at the RSPH** | | |
|---|---|---|
| Yes | 9 | 4.3 |
| No | 201 | 95.7 |
| **Total** | **210** | **100.0** |
| **If No List of** the **unavailable services** | | |
| Specialized services | 135 | 64.3 |
| Drugs other than chemotherapy | 134 | 63.8 |
| Diagnostic Tests | 122 | 58.1 |
| Chemotherapy | 103 | 49.0 |
| Surgery | 50 | 23.8 |
| Laboratory tests | 50 | 23.8 |
| Radiation | 36 | 17.1 |
| Imagining Test | 18 | 8.6 |
| PET scan | 5 | 2.38 |
| Bone marrow transplant | 7 | 3.3 |

### 4.2.3 Essential and complementary drugs

As shown in table 4.4, 49% of participants reported that there is shortage in chemotherapy, 63.8% reported that there are shortage in complementary drugs (antibiotics, analgesic, oral gel and suspension) for children with cancer. Access to essential medicines is one of the essential global problems, with 30% of the world's population lacking regular access to essential medicines (WHO, 2004).

When asked the pharmacist in chemotherapy pharmacy about essential medicines said '*We keep a steady stock of essential drugs for the children. If a specific treatment is about to end, we inform the PCRF to provide it before its end, in order to ensure the treatment plan and to arrange the referral matters early if appropriate treatment is not available*'.

A Consultant oncologist mentioned that '*There is shortage in PEG-asparaginase, L-asparaginase, monoclonal antibodies, rituximab and procarbazine therapies. Sometimes we have to use alternative medicines but if the patient is sensitive to the alternative medicine, the treatment cycle is stopped until appropriate therapy is available so there are missed doses. The interruptions we have in therapy drugs, inhibit us from seeing the results*'. Also, the head of nurse department said *'In Gaza, there is a shortage of chemotherapy and even medicines used for the side effects of chemotherapy, there is no nystatin oral suspension, miconazole oral gel, antibiotic, anti-emetic and sometimes even the paracetamol is not present. The patients with cancer receive their complementary*

*drugs in MOH as a symbolic price of 3 shekels per sort but sometimes patients resort to private sector to compensate lack of services*'. Another pharmacist added his comment '*We are in the hospital buy complementary medicines directly from the pharmaceutical company if are not available at the MOH*'. For Gaza in 2014, there is chronic shortage in 26% of essential medicines in Gaza (zero stock). That it could be related with the siege, political division, financial instability and procurement constraints due to political agreements with Israel (Daher, 2015).

We conclude that there is a shortage of essential and complementary medicines and that this shortage negatively affects quality of care and good outcome.

### 4.2.4 Evaluation of pediatric cancer diagnosis

As shown in table 4.4, 58.1% of participants reported there are shortages in diagnostic tests and these tests have been done outside Gaza. As the Key informants all agree that '*The problem in diagnosis of pediatric cancer especially leukemia, is not in the initial diagnosis, but in confirming the diagnosis and confirming the type of cancer, as most cases are correctly diagnosed at RSPH, but these cases need to know the type of disease, so the cases are referred outside Gaza to confirm the type of disease*'.

A consultant oncologist when asked about diagnosis said '*There are no fish studies, flow cytometry (Immunophenotyping), PET scan, MRD and some of immune stains (Immunohistochemistry) in Gaza strip, so the cases are referred outside Gaza. In addition, RSPH has one CT device and no MRI despite has a place dedicated to MRI" and he added that "The presence of MRI is good because communication with radiology department in Al-Shifa hospital for children referral to MRI is difficult than surgery referral due to long waiting list*'. As in table 4.4, 8.6% of participants reported that the imaging tests are not always available in RSPH. The consultant hematologist who works in providing pediatric cancer services added his comment about this '*It is assumed that RSPH has one MRI device due to the presence just of two MRI devices in Gaza and the load on them high from high number of patients and sometimes there is a malfunction in the one of MRI devices* which leads to long waiting list'.

A Key informant in MOH commented about the availability of MRI and CT devices by saying '*There are four MRI devices, two in the MOH hospitals and two in the non-governmental hospitals (There are 2 MRI devices per million'.* Which is considered low

compared to the ratios in 2019 in Turkey 10.92, occupied Palestinian territories 5.08, Italy 30.22. In 2020 34.54 in United states per million (OECD, 2021a). He added, '*For CT, there are 8 in the governmental hospitals'.* Wehedi (2019) study revealed that there are 8 CT devices in the governmental hospitals and 6 in the non-governmental hospitals in Gaza, in addition, one in Al Salam hospital in Rafah with total 15, which represent 7.5 per million. When comparing the number of CT with ratios in other countries, 9.72 in occupied Palestinian territories per million, 18.17 in France, 14.69 in Turkey in 2019 and 42.43 per million in United states in 2020 (OECD, 2021b).

Another Key informant when asked about diagnostic and laboratory tests said '*Basic laboratory services and some of advanced tests are found in RSPH but if the child needs to do more advanced tests, they are done in Hayat hospital or in private hospitals inside or outside Gaza'.* As shown in table 4.4, 23.8% of participants reported that there are shortages in laboratory tests in RSPH. Another Key informant added '*The number of histopathology labs in MOH is low and the load on them is high so, the patient waiting approximately one month to get the result. So, sometimes the caregivers of patient do the histopathology in private labs to get the result in one week'. and he added that 'Diagnostic devices that are not available in Gaza may be available, but there are no trained personnel on these devices and there are no updates to deal with these devices'.* Pharmacist commented on that '*Basically, it is assumed all diagnostic devices are available in RSPH due to RSPH is a specialized third-class hospital to localize service and reduce referrals, but the patient is referred to confirm the diagnosis to begin that treatment properly and this is in the interest of the patient*'.

On the other hand, a nurse said '*The government in Gaza does not have to bear the responsibility for wrong diagnosis, and tell us that any case has cancer whether easy or difficult case, refer them outside Gaza and government in Ramallah bears the responsibility'.* He added, *'I hope the diagnostic devices will be available to decrease patient referrals to the abroad, for example, in the period of existence of corona virus, if the patient is referred abroad may be infected by virus*'.

We can conclude that there is absence or obvious shortage of diagnostic tools which leads to long waiting lists or patient referrals abroad which affects the quality of care.

### 4.2.5 Health information system

The health information system provides the basis for decision making and has four main functions, data generation, collection, analysis, synthesis and communication and use of data (WHO, 2008). A Key informant when asked about health information said '*There is no cancer research center and the research done individually. There is no enough financing or incentives to improve the research in Gaza*'. She added, *'We don't have electronic cancer registration system and we lack the surveillance system about cancer in Gaza. We obtain data about children with cancer from their medical files inside the hospital*. In addition, *every year we register incidence rate, the number of total pediatric cancer cases and the number of deaths but in last 2 years we did not register these numbers because we did not go to hospitals to record these numbers due to the Corona virus pandemic. Every 5 years a report is issued showing the statistic of the number of pediatric cancer patients diagnosed within five years*'. An interviewed consultant oncologists when asked about health information system said '*We don't have effective cancer health information system and registration system and current system should be more developed and more accurate due to decisions are made based on the available information*'.

A nurse added her comment '*The cancer registry is the only place for cancer information. But there is no interest from the cancer registry center to record the number of children diagnosed with cancer and the number of children who receive monthly pediatric cancer services within the pediatric department*'.

A Pharmacist who works in chemotherapy pharmacy said when asked about the health information system said '*We lack a computerized system and programs, in which the treatment protocol is displayed once the diagnosis is entered and the chemotherapy doses are displayed once the surface area is entered*'.

From the qualitative data, there are gaps in research activities in Gaza and there is absence of motivating factors to stimulate the research in Gaza. Although the important of cancer registry, it has problems with data accuracy, which may be related to poor coordination with the main hospital of pediatric cancer and other pediatric oncology services provider and incompleteness of medical records.

### 4.2.6 Treatment modalities

There are multiple methods for treatment of cancer patients, including surgery, radiation, systemic therapy or combination. In developing countries, access to care whether surgery, radiation or systemic therapy may not be available. Most cancer centers in developing countries use modified treatment systems derived from those used in developed countries (Cazap et al. 2016).

Countries have different capacities for cancer care, depending on the availability of resources. Low- middle countries have inadequate resources for health care, which may affect the mortality rates (Horton & Gauvreau, 2015).

**- Surgical treatment**

The table 4.4 showed that about 23.8% of caregivers of children diagnosed with cancer reported that the surgery service is not available in RSPH and their children received the surgery service outside Gaza. This is congruent with what the nurse said when asked about the surgery service '*The problem in the absence of surgery department, that leads to the referral all cases of children who need surgery, most cases are referred outside Gaza and few cases to Al- Shifa hospital. There is supposed to be a pediatric cancer surgery department in RSPH and presence of a team of specialized surgeons and an anesthesiologist due to there is no anesthesiologist to perform anesthesia before bone marrow biopsy in oncology pediatric section and the nurses themselves do this task as instructed by the doctor*'. But The pharmacist commented on that '*It is difficult to establish the surgery department at RSPH because it needs huge building, human cadres and many of equipped operating rooms*'. In addition, most of the key informants said '*The surgery for pediatric cancer is considered general surgery. there are no specialized pediatric cancer surgeons in Gaza and there are no specialized surgeons for Port-A-Cath installation and removal although it can be installed and removed in Gaza but that still needs more capabilities, training and updating related to dealing with Port-A-Cath*'.

A consultant oncologist added '*Most of patients who need surgery are referred abroad due to they need radiotherapy after surgery and there is no radiotherapy in Gaza such as in the case of brain cancer, where patients need surgery and radiation, therefore, the patient needs to be referred abroad for surgery and radiotherapy*'. This saying was also supported by a key informant as he said '*Most of the children who are referred abroad for surgery*

*suffer from brain cancer due to brain surgery is delicate and sensitive and there is a lack of capabilities and staff in Gaza. brain surgery requires a specialized surgeon and post radiation and post follow up*'.

An interviewed surgeon when asked about the surgery service said '*I am not a specialized surgeon, but I try to keep up with latest updates on childhood cancer operations, and I can do many of them within my capabilities without problems but we have problem with rhabdomyosarcoma and we can operate palliative surgical treatment'. Added his comment "there are 26 general surgeons for pediatric surgeries, they can perform pediatric cancer surgeries, but under the supervision of approximately two a qualified surgeon*'.

**-Chemotherapy treatment**

As shown in table 4.4, 49% of caregivers of children diagnosed with cancer reported that the chemotherapy not always available in RSPH and 79.5% of children with cancer get chemotherapy at RSPH. Majority of key informants informed that '*Since opening the Mousa and Suhail department (pediatric hematology and oncology department) about two years ago, more than 90% of chemotherapy is provided Periodically by the PCRF in cooperation with the Ministry of Health'.*

A consultant hematologist who works in providing of pediatric oncology services added '*RSPH can provide chemotherapy treatment for its patients, but doesn't provide radiotherapy*'.

The pharmacist who works in chemotherapy pharmacy said '*If there is an imminent shortage of a particular chemotherapy for a specific protocol, the pharmacy is notified, the patient is referred abroad for the rest of doses as mentioned in the protocol. If there is difficulty in referring and crossing the child to the west bank or occupied Palestinian Territories, the child's treatment is stopped for a period of time and that affect treatment efficacy, or the child is given another chemotherapy treatment from another protocol that fulfills the purpose and this happens little because it is supposed patients take their medication as is'.* This is explained by another oncologist as he said '*If the child is given another chemotherapy treatment from another protocol, which may adversely affect effectiveness of treatment'.*

**-Treatment by Radiotherapy**

About 17 % of caregivers indicated the radiotherapy is not available at RSPH, not even in Gaza as shown in table 4.4. In Skaik (2013) study that was conducted at the oncology departments and out-patient daily care of the cancer clinics in three hospitals (Al-Shifa, Rantissi and European Gaza hospitals), 5.8% of the patients received radiotherapy abroad. Key informants all mentioned that '*Radiotherapy is not present in Gaza, and could not be present in Gaza duo to political reasons and the absence of radiotherapy treatment and PET scan in Gaza represented a barrier in cancer control in some cases*'.

Consultant oncologist talked about the importance of radiotherapy '*It is supposed to start radiotherapy as soon as possible after some types of surgery, so cases that need surgery are referred to Occupied Jerusalem due to need radiotherapy and this a modality is not present in the Gaza Strip*'. He added that '*Treatment by radiotherapy in Al-Mutlaa Hospital for pediatric and adult Through contracting or purchasing the service by the Ministry of Health*'.

**-Bone marrow transplant**

The table 4.4 showed that 3.3% of caregivers reported that a bone marrow transplant abroad procedure is not available in RSPH, not even in Gaza.

Key informants all agree, it is difficult to perform bone marrow transplant procedure due to it is complicated procedure and need for specialists and high qualified training.

**Table (4.5) Distribution of responses by service delivery related variables**

| | | |
|---|---|---|
| **There is place other than RSPH to receive services regarding children cancer** | | |
| Yes | 177 | 84.3 |
| No | 33 | 15.7 |
| **Total** | **210** | **4.5** |
| **The place to receive services other than RSPH** | | |
| Jerusalem | 84 | 47.5 |
| West Bank | 71 | 40.1 |
| Inside occupied Palestine 1948 | 24 | 13.6 |
| Outside country | 5 | 2.83 |
| **The child patient with cancer gets his chemotherapy dose in RSPH** | | |
| Yes | 159 | 79.5 |
| No | 41 | 20.5 |
| **Total** | **200** | **100.0** |

*Table (4.5a): Continued*

| | | |
|---|---|---|
| **The child patient with cancer gets his chemotherapy dose in other Places** | | |
| Yes | 151 | 75.5 |
| No | 49 | 24.5 |
| **Total** | **200** | **100.0** |
| **The place to receive chemotherapy other than RSPH** | | |
| | | |
| West Bank | 67 | 44.4 |
| Jerusalem | 61 | 40.4 |
| Inside occupied Palestine 1948 | 21 | 13.9 |
| Outside country | 4 | 2.65 |
| **the child patient with cancer gets his drug/s from RSPH** | | |
| Yes | 151 | 81.6 |
| No | 34 | 18.4 |
| **Total** | **185** | **100.0** |
| **the child patient with cancer gets his drug/s from Other Places** | | |
| Yes | 139 | 76.0 |
| No | 44 | 24.0 |
| **Total** | **183** | **100.0** |
| **The place to get drug other than RSPH** | | |
| Pharmacy | 117 | 84.2 |
| Jerusalem | 5 | 3.6 |
| West Bank | 12 | 8.6 |
| Inside occupied Palestine 1948 | 2 | 1.4 |
| Outside country | 3 | 2.2 |
| **Total** | **139** | **100.0** |
| **Availability of chemotherapy doses every time at Rantissi hospital** | | |
| Yes | 125 | 64.4 |
| Not all the time | 38 | 19.6 |
| No medication available | 31 | 16.0 |
| **Total** | **194** | **100.0** |
| **Availability of the drugs every time in Rantissi hospital** | | |
| Yes | 43 | 24.4 |
| Not all the time | 108 | 61.4 |
| No medication available | 25 | 14.2 |
| **Total** | **176** | **100.0** |

### 4.2.7 Standards/guidelines

A national cancer control program is a public health program designed to decrease the cancer incidence, cancer mortality and enhance the QOL of cancer patients (WHO, 2002a). A national cancer control program is an integrated set of activities covering prevention, diagnosis, therapy, palliative care, cancer registration and research, such programs should be reviewed and contributed between all the stakeholders and supported by the MOH (WHO, 2009)

The head of nursing department when asked about the protocols application said *'We follow unified protocols in Gaza and the West Bank and these protocols are released by international countries and certified by WHO, and there are even protocols for follow-up after chemotherapy. The protocols are found in the hospital and within the reach of the staff. The majority apply the protocols because there is no opportunity for any margin of error' He added 'There are cooperation and understanding between the medical staff, if the nurse doesn't understand certain protocol, the nurse asks the doctor about it, and the doctor tells the nurse what is required and every day there is follow-up for the chemotherapy schedules for patients*'. A pharmacist who works in chemotherapy added about it '*For sterilization, we follow the protocols and the final concentration of chemotherapy is according to the protocol and the error in preparing the chemo is zero*'.

A consultant oncologist indicated that '*The WHO protocols are applicable depending on what is available in the Gaza Strip and effective especially with presence of PCRF and availability more than 90% of chemotherapy. We always try to get the latest updates about pediatric cancer management but that need to travel and attend conferences abroad to get the latest updates continuously. We have a problem of not paying attention to the medical staff travelling to attend conferences and see the latest developments, as well as the problem of travel difficulties due to political situation*'. A consultant hematologist also commented on this by saying '*The most of chemotherapy protocols are applicable except in cases of high-risk leukemia, they are referred abroad to AL-Motalea hospital and if there is shortage in one part in protocol, the case is referred abroad*'.

The interviewed surgeon when asked about the protocol application said '*We have a strategy for pediatric cancer management and it is applicable, a while ago we used to follow the American protocol by starting with surgery then chemotherapy, but now we*

*follow the European protocol by starting with specific sessions of chemotherapy then operating the surgery*'.

The nurse added her comment about policies application by saying '*At Al-Hussain hospital, the staff all follow the policies, but in RSPH we are follow routine working, I mean, we follow our experience in working Regardless of the application of policies. We started to apply the policies that we are learned inside the Al-Hussain hospital such as Blood withdrawal policy, chemotherapy policy, but they are not written, and currently they are working on writing them under the title of security and politics' She added that 'The medical staff in Al Hussain hospital are not most efficient of us at work, but all of them work on policies but if you want to implement the policies in a new way, there must be a sufficient number of staff. We are approximately 4 nurses dealing with 50 cases per day in day care, so there is no time to implement all the policies and sometimes even the nurse cannot wear gloves* during work'.

We conclude the medical staff follow the international protocols for treatment, chemotherapy preparation and surgery but there are shortages in application of working policies. There is no interest to the travel of medical staff to attend conferences and get the latest updates about protocols for pediatric cancer management.

### 4.2.8 Evaluation of building and physical space of facilities

There is a direct proportional relationship between the building design and the patient physical and emotional outcome, as it could assist to improve sleep and to reduce pain in addition to Increase staff effectiveness, reduce medical errors, and increase staff satisfaction (Zimring, Joseph & Choudhary, 2004). The physical environment plays a major role in the healing process and well-being and this have been proved to be increasingly relevant for patients and their families as well as for healthcare staff. The well- built environment can reduce errors, falls and infection rate and can enhance control, improve privacy and comfort (Huisman, et al, 2012). As shown in table 4.19 that will come later on page 83, 88.4% of participants reported that pediatric hematology and oncology department is equipped with modern and up-to date equipment. 91.2 % of them reported the hospital environment is comfortable and 92.8% perceived the nature of place is suitable for children.

What the researcher observed is congruent to what the Key informant said when asked about building and physical space of facilities *'The pediatric hematology and oncology department is built on an area of 1,400 $m^2$ with 24 -hour air conditioning and 24- hour electricity and water. There are 16 inpatient beds within the rooms, 16 chairs in day care. If the child stays in the section there is isolation between the patients, as each child has a separate room with a bathroom. there is a small school where lessons are provided for those who did not go to school due to treatment and there are three examination rooms, a meeting room and space for games and activities*. Recently there is a small dental clinic with one bed to follow up the dental health of children with cancer'. We found that Gaza has only 0.04 bed per 1000 children under 12 years. Which consider very low percentage in comparison to other countries. In 2019 for the total hospital beds in Turkey have 2.88, France 5.84 per 1000 populations, in 2020 the total hospital beds in Belgium 5.54 and in occupied Palestinian territories 2.91 (OECD, 2021c).

The pharmacist in chemotherapy pharmacy said that '*The chemotherapy pharmacy is set up according to international standards'.* While regarding the pathology unit in Al-Shifa hospital, a chief pathologist reported '*The place where we are working is not suitable for working environment (خرابة), we are promised to move to another site since a long period of time, but nothing new'.*

From the collected data, we can conclude that the pediatric hematology &oncology department is suitable and comfort for children. The place is clean and patient privacy is guaranteed but there is shortage in rooms and beds. The building design of chemotherapy pharmacy is appropriate but the pathology building in Al-Shifa hospital is very bad.

### 4.2.9 Health workforce

#### 4.2.9.1 Workforce number

As shown in table 4.19, that will come later on page 83, most of caregivers think the human resources are adequate in number with a mean of 70.3 . WHO (2006) found that 57 countries with absolute shortage of 2.4 million physicians, nurses and midwives per 1,000 population and this is a main barrier to providing the basic health services.

A key informant said '*There is a shortage of doctors, there are only two pediatric oncologists in the hematology and oncology department in RSPH. There is a shortage of pharmacists in the chemotherapy pharmacy, two permanent and two temporary pharmacists. sometimes there were interns, but they quickly left. there is no nutritionist nor permanent psychologist*'. He added that '*The number of all oncologists for adult and pediatric in Gaza are 10',* which represent 0.5 per 100,000. He added, 'The number of oncologists for pediatric only are 2', which represent approximately 0.25 per 100,000 of children under 12 years. This is considered very low with the international ratios. As the oncologists in Europe are 3 per 100,000, 2 per 100,000 in Eastern Mediterranean and 0.1 per 100,000 in Africa (Alwan, 2001). The Oncologists in Australia in 2009 as 1.4 per 100,000 and 3.5 per 100,000 in United States (Blinman & et al, 2012).

A pharmacist added '*In the chemotherapy pharmacy we have a deficiency. We need also at least 2 pharmacists to relieve the pressure when preparing chemotherapy because there are supposed to be 6 pharmacists, but in the chemotherapy pharmacy there are two permanent and two temporary pharmacists*'.

For the general practitioners number in the pediatric hematology and oncology department in RSPH, a consultant oncologist said '*There is only one GP, it is assumed to be also another one GP at least to take on some of the workload. This shortage indicates the negligence of MOH to the pediatric hematology and oncology department and preventing the training dimension of such graduates. The number of nurses is appropriate in the presence of nurses working temporarily, but this does not solve the problem. Because nurses who work temporarily when they know the full working conditions, their contract ends and new people come in and this problem continues*'.

A consultant oncologist added his comment about health workforce by saying *'We have no nutritionists in RSPH who care for the children with cancer or cancer patients in general, bad nutrition has harmful effect on oncological therapy. It is assumed to be nutritionists to monitor meals provided to children in hospital, to inform parents about foods that are not allowed with chemotherapy due to low immunity of their children with cancer in chemotherapy treatment period, and existence of nutritionist is important to provide parenteral nutrition for patients who need it, in addition the we always ask for integrated services because it saves the patient from suffering and is important in the cases of the patient who needs the intervention of the specialist*'. Good nutrition and nutritional therapy

seem to have beneficial effects on the oncological therapy. a close collaboration between nutritionists, doctors and nurses will be important to achieve good results (Ose & et al, 1998).

A nurse when asked about the health workforce said that '*The doctor takes a sample of bone marrow after I give the anesthetic injection to the patient by order of the doctor, although this is not my specialist, but I do this because there is no anesthetist*'.

Another nurse said '*The number of oncologists and nurses in this section is small, and the increasing in the number of cases puts pressure on the staff, and this may make the contact time with the doctor is short. At Al-Hussein Hospital, there are two nurses who supervise each case and a specialized team of anesthesiologist and Anesthesia technician who anesthetizes the patient in a special operating room when performing a bone marrow biopsy, But at RSPH, we are the ones who do this mission, although the anesthesia of the patient is sensitive because it depends on the weight of the patient, vital signs and body index and it is assumed that there is a psychologist to support children with cancer continuously. sometimes notice certain strange behaviors on children with cancer so we tell the team of psychological support to sit with them, but their support is not continuous, in addition that, there is no nutritionist in the pediatric oncology section, but we are as nurses try to guide people about healthy eating habits when taking chemotherapy doses'.* She added that *'There is assumed to be an increase in the number of nurses, doctors and we need a competent medical secretary who can make referrals to other hospitals from the section itself and quickly*'. Another nurse indicated that '*Many of nurses escaped from the hematology and oncology department because the world of blood and oncology is large and needs great knowledge and experience and the working inside oncology &hematology department is tiring and exhausting, which led to a shortage in nurse numbers'.*

Another key informant talked about this '*Nurses always sympathetic to patients. They are always tense and suffer from workload. All this affects nursing staff but it doesn't affect the provided services because the provider deals with the patient in right way'.*

The head of nurse department said '*We lack the issue of organizing the work because the lack of capabilities, it is assumed that everyone knows their work and that there is a specialized team for everything. I am an employee follow to the Ramallah government . Currently, I am on financial retirement list and get 50% of my salary and have no dues,*

*which frustrates me and the employess with the same problem. Unfortunately, governments did not care about teams, and slaughtering us Instead of helping us. there is supposed to be a nurse for every two children, in our section, there are 2 nurses with 8 cases all night for taking samples and installing chemotherapy and for many duties. We do the work of doctor and Physiotherapist. We were 25 nurses but now become 11 in pediatric section. how do you want us to cover work in the morning and evening periods? Sometimes there are nurses working temporarily but when they know the full working conditions, their contract ends. In addition, there is assumed to be psychological discharge for the medical staff and motivate them by evaluating their works and providing them rewards*'.

The interviewed surgeon in Al- Shifa hospital said regarding health workforce '*We don't have oncology specialized surgeons in Gaza. We are general surgeons, our numbers approximately are 26, all surgeons can perform pediatric cancer surgery, but under the supervision of approximately two a qualified surgeon to perform pediatric oncology surgeries*'.

A Pathologist in Al- Shifa hospital reported that the pathological department at Al-Shifa is considered as the largest department of pathology in the MOH and the private sector, which receives at least 7000 cases annually and 600 cases monthly which is considered a large number compared to the number of pathologists in this department, which is 3, two of them permanent pathologists and one part-time pathologist, and the total of histo-pathologists in governmental hospitals of Gaza are only 6 distributed in Al-Shifa hospital, European hospital and Naser hospital. Gaza has only 0.3 pathologists per 100,000 which is considered low with international ratios, in 2007, 5.16 pathologists per 100,000 in United States and 4.46 pathologists per 100,000 population in Canada. In 2017, 3.94 pathologists per 100,000 population in United States and 4.81 pathologists per 100,000 population in Canada (Metter & et al, 2019).

In conclusion, the shortage of human resources not only in the oncologists, but also include oncology specialized nurses, onco-surgeons, anesthesiologists, chemotherapy pharmacists, psychologists, pathologists and nutritionists.

#### 4.2.9.2 Training for health workforce

As shown in table 4.19, that will come later on page 83, Majority of caregivers think the available human resources have the needed qualifications with a mean of 81.4. The main objective of workforce development is to produce sufficient number of qualified staff with technical competencies and social attributes make them accessible and facilitate their ability to reach diverse clients and population (WHO, 2006). Competent health workers with the effective multidisciplinary health workforce form core of efficient and high-quality health system (WHO, 2012). To achieve the countries the positive effect on health outcome, it needs to develop effective health workforce training and education that has capacity to produce and improve health workers (Ibid).

Commenting on health workforce training, a key informant said '*In the last period before the Coronavirus pandemic, a doctor, a nurse and a pharmacist were sent to Al-Hussein Hospital in Jordan for training*'. A nurse supported the key informant's saying as she said '*Since the opening of the pediatric, we have started receiving training abroad at Al-Hussein Center, and currently there is training in the form of lectures and we undergoing pre-and post-exams*'.

Another interviewed nurse said '*We took a course on the intensive care unit, but I think that is not necessary for us because we do not need to do a resuscitation if the child has arrived in intensive care. they promised us more training courses. but with Corona pandemic everything has stopped. Currently, in a new system, PCRF give us lectures by program known as for kids in our specialization and they give us a test before the lecture and after the lecture' She added 'I would like to train us on the topics that were not covered and we did not practice them, such as bone marrow transplantation and about intensive chemotherapy*'.

A pharmacist in chemotherapy pharmacy answered when asked about this '*The training at Al-Hussein Center focused on policies, operations, and drugs that we only see in books and focused on the workplace specification system. On the contrary, at RSPH There is no training but the system almost depends on self-training*'. In contrary to the previous saying, another pharmacist said '*In-service training for pharmacists in the pharmacy is conducted continuously, and there is a pharmacist traveled abroad and attended a course at Al-Hussein hospital'.*

The head of nurse department supported the previous saying about training '*We were doing in service training for new employees in this section but we ourselves need training on new things. We did not know them and we did not hear about them in the world of cancer because every day there is progress and every day there is new something in the world of cancer*'.

A consultant oncologist added his comment '*Due to political situation and siege, we can't have the simplest right which is training or scholarships abroad, this can prevent us from improving our qualifications'.* The surgeon in Al-Shifa hospital commented on that '*The MOH is not interested in sending doctors abroad for training courses or scholarships in pediatric oncology surgery, I personally try to coordinate to travel the doctors for training courses, scholarships and specialization*' He added about in-service training, '*There are doctors who accept training and there are doctors who do not, so I always say to those who want to learn and train. Ethics first, then the desire to learn, then science'.*

In conclusion, we can consider the training as an important step to improve pediatric cancer management especially in surgery, oncology, pathology and palliative care. The political situation represented by siege and division limit the travel abroad for training and scholarship.

#### 4.2.9.3 Knowledge and experience

The nurse when asked about the knowledge and experience said '*I think there should be a continuous update of the information and knowledge of the staff'* She added *'For the new nurses when come in to hematology and oncology department, I feel that they don't have enough skills and experiences'.* According to Choudhry& et al. (2005), the doctors who have been in practice for more years and older doctors have less factual knowledge, are may be at risk for providing lower-quality care, and may also have poorer patient outcomes.

The head of nurse department said '*Our knowledge, skills are continuously updated due to that we receive lectures on computers and mobile phones, and we follow up new cases that come from abroad. The experience we have is high due to the number of working years and the number of children with cancer cases*'. A nurse added about this topic '*We have enough experience, but every day we still learn new something we haven't heard before'.*

A pharmacist said '*The staff in Al-Hussain center don't have better experience than us, but their skills are high due to they have a specialized center, existence of equipment and devices and they have permanent training and workshops*'. Another pharmacist added on that '*When the pharmacist trained at Al-Hussein, he did not find them better than him in experience, but he learned from them the policies and protocols that they have, and how the system working. Pharmacists in RSPH always keep up the latest updates and they modify some information for doctors due to we have high knowledge*'.

In conclusion, there is an inverse relationship between knowledge and the number of years that physicians had been in practice, but the lectures that are provided to the medical staff in oncology department may reduce the information loss.

### 4.2.10 Medical files

The medical record is considered complete if it contains enough information about the patient. But after evaluating the completeness of 210 medical files in the main hospital providing pediatric cancer services using the checklist in Annex 3, it was found there were defects in completeness of medical records with the total average percentage of completeness of 59.99%.

Documentation of patient demographic data is important to identify the patient. As shown in table 4.6, 87.6% of files have patient Name in all pages of medical files. When comparing our findings with a study conducted in the main hospitals involved in providing colorectal cancer services in Gaza Governorates, we found 99% of medical files have patient name in more than the two thirds of the number of pages of medical files (Wehedi, 2019), which not the same which what we had due to that we evaluated the completeness of patient name in all pages of medical record. For the patient's identification, 49% of files have patient's identification in all pages of medical files. The age variable is the lowest completeness in demographic data, only 11% of medical files have the age in all pages. For the date of birth, 34.8% files have patient date of birth in all pages of medical files. In study of Wehedi (2019), only 3% of medical files have patient date of birth in more than the two thirds of the number of files. For the patient's gender, only 19.5% of medical files are complete, while 17% of medical records of colorectal cancer patients in the Gaza Strip have the patient's gender recorded in more than the two thirds of the number of pages of medical file (Wehedi, 2019).

**Table (4.6) percentage of completeness of demographic characteristics in the medical files of children with cancer in RSPH in the Gaza Strip**

| | Not filled | | Partially filled | | Completely filled | | Mean | MD | Std |
|---|---|---|---|---|---|---|---|---|---|
| | N | % | N | % | N | % | | | |
| Patient's name | 0 | 0 | 26 | 14 | 184 | 87.6 | 97.4 | 100 | 8.78 |
| Patient's identification | 0 | 4.8 | 97 | 46.2 | 103 | 49 | 77.9 | 81.7 | 26.8 |
| Total | Mean=87.65, MD=90.00, Std=14.85 | | | | | | | | |
| Patient's age | 145 | 69.0 | 42 | 20 | 23 | 11.0 | 21.03 | 0.00 | 34.17 |
| Patient's Date of birth | 2 | 1. | 135 | 64.2 | 73 | 34.8 | 79.46 | 83.33 | 20.56 |
| Patient's gender | 17 | 8.1 | 152 | 72.4 | 41 | 19.5 | 57.43 | 50.0 | 29.02 |
| Patient's address | 22 | 10.5 | 221 | 57.6 | 67 | 31.9 | 60.71 | 50.0 | 30.99 |
| Home telephone | 95 | 45.2 | 65 | 31 | 50 | 23.8 | 39.52 | 50.0 | 40.38 |
| Total | Mean=51.36, MD=52.0, Std=16.83 | | | | | | | | |

As shown in table 4.7, The author's identification presented completely in 40.5% of medical file and in the rest of medical files presented as incomplete, which may need more efforts to motivate health care providers to document their work to protect themselves from legal issues. The clearance of the consultation report is important to be evaluated in the medical files, which is important to understand conclusions about the case, what should be done and appointment of next follow up. the 66% of medical files are with clear of consultation report and the rest with no clear consultation. In Wehedi (2019) study, 92% of medical files with clear consultant report. In 74.8% of medical files, dates are recorded completely. Diagnosis plan completeness represent 66.2% and discharge summaries represent 93.6%. which is good but need more concern to improve the quality of provided for patients. When comparing it with the medical records of colorectal cancer patients in the main hospitals involved in providing colorectal cancer services in Gaza Governorate, in 91% of files, dates are recorded completely in more than the two third of the number pages of medical files. It was found that 76% of medical files showed the diagnosis plan completeness and 89% showed the completeness of discharge summaries (Wehedi, 2019). The ICD10 was completed in 8.5% of medical files in the total sheets of discharge, emergency and outpatient, and was partial completed in 77.8% of medical files, as recorded in discharge sheets only. The results are nearly same the results of Abu Dagga (2014) study, which showed the completeness of ICD10 in discharge sheets is 74.9%. The hematologist who works in providing pediatric cancer services when asked about ICD10, explained that 'We always try to write the ICD-10 for each type of childhood cancer,

especially on the outpatient sheet. ICD filling is the responsibility of any physician anywhere'.

There are no electronic medical records for children with cancer. The surgeon commented on that 'We need to turn the paper files to electronic files to network the data of patients easily and to keep the patient's file for fear of losing any paper from the file'. EMR can play a greater role in making medical decision, coordinating services of different departments, categorize care to the patients, decreasing medical errors, improving quality, decreasing costs, etc. Moreover, the EMR can effectively assist to transmit patient information from one institution to another and thus aiding in referrals and improving the access to healthcare (Okapala, 2013).

**Table (4.7) percentage of completeness of medical record domain in the medical files of children with cancer in RSPH in the Gaza Strip**

| | **Not filled** | | **Partially filled** | | **Completely filled** | | **Mean** | **MD** | **Std** |
|---|---|---|---|---|---|---|---|---|---|
| | **N** | **%** | **N** | **%** | **N** | **%** | | | |
| Chief compliant | 21 | 10.8 | 23 | 11.8 | 150 | 77.3 | 84.0 | 100.0 | 32.6 |
| Professional diagnosis | 10 | 4.8 | 47 | 22.6 | 151 | 72.6 | 89.0 | 100.0 | 23.8 |
| Is ICD10 used? | 24 | 12.1 | 158 | 77.8 | 17 | 8.5 | 42.9 | 33.3 | 25.0 |
| Diagnosis plan | 71 | 33.8 | 0 | 0.0 | 139 | 66.2 | 66.2 | 100.0 | 47.4 |
| Author's identification | 4 | 1.9 | 121 | 57.6 | 85 | 40.5 | 85.4 | 88.9 | 18.9 |
| Dated entry | 1 | 0.5 | 52 | 24.8 | 157 | 74.8 | 94.9 | 100.0 | 12.1 |
| Electronic MR | 210 | 100 | 0 | 0.0 | 0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Note or report from the consultant in the record | 71 | 33.8 | 0 | 0.0 | 139 | 66.0 | 66.5 | 100.0 | 47.3 |
| Discharge summaries | 12 | 6.4 | 0 | 0.0 | 176 | 93.6 | 93.6 | 100.0 | 24.5 |
| Total | Mean =70.1, MD=72.1, Std=12.5 | | | | | | | | |

Regarding medication sheet as shown in table 4.8, 80.3% of medical records contain the complete medication records (dosages and dates). The researcher found 0.5% of medical files shows allergies the patient may have. 0% of medication record referred to the side effects of the medication, which reduce the quality of medical records and increase of medical errors. Which is compatible with the result of Wehedi (2019) study which showed that 0% of medical files talked about allergies the patient may have, also 0% of them shown the side effects of medication.

**Table (4.8) percentage of completeness of medication record domain in the medical files of children with cancer in RSPH in the Gaza Strip**

| Items | Not filled | | Completely filled | | Mean | MD | Std |
|---|---|---|---|---|---|---|---|
| | N | % | N | % | | | |
| Medications are documented for each visit | 33 | 17.6 | 154 | 82.4 | 82.35 | 100.0 | 38.2 |
| Medication record | 37 | 19.7 | 151 | 80.3 | 80.32 | 100.0 | 39..86 |
| Medication side effect | 188 | 100 | 0 | 0 | 0.0 | 0.0 | 0.0 |
| Allergies and adverse reactions | 187 | 100.0 | 1 | 0.5 | 0.53 | 0.0 | 7.29 |
| Mean = 40.8, MD = 50.0, Std 19.36 | | | | | | | |

Documentation the patient's history is important to collect more information about patient's history, it also helps health care providers to deal with the patient properly and determine the appropriate treatment plan. As shown in table 4.9, general examination recorded completely in 74.9% of medical files. There are 60.4% of medical files have medical-surgical history which is important to increase quality of care provided to patients.

The percentage of documentation of family history which considered important in the patient's treatment plan is 24.5%, which may negatively affect the care provided to patients. The researcher may explain the result due to the workload, limited human resources and limited time. When comparing our results with the results found after reviewing of medical records of colorectal cancer patients in the main hospitals involved in providing colorectal cancer management, general examination recorded completely only in 47% of medical files, 35% of the files had medical-surgical history and 0% of medical files with family history (Wehedi, 2019).

When asked key informant about history and physical examination domain completeness said "*If* every doctor tries to complete his patient 's file including patient's history and physical examination. It helps a lot in treatment plan and understanding the full story of the patient on a long term"

**Table (4.9) percentage of completeness of history and physical examination domain in the medical files of children with cancer in RSPH in the Gaza Strip**

| Items | Not filled | | Completely filled | | Mean | MD | Std |
|---|---|---|---|---|---|---|---|
| | N | % | N | % | | | |
| Family history | 142 | 75.5 | 46 | 24.5 | 24.5 | 0.0 | 43.1 |
| Medical- surgical history | 74 | 39.6 | 113 | 60.4 | 60.4 | 100.0 | 49.0 |
| Physical exam | 47 | 25.1 | 140 | 74.9 | 74.9 | 100.0 | 43.5 |
| Mean = 53. 3, MD = 66.67, Std 34.99 | | | | | | | |

There are 95 children were taken chemotherapy during the study period which conducted at RSPH so it is important to examine the chemotherapy request. It should have some important items such as body weight, height and surface area to calculate the chemotherapy dose correctly. The vast majority (97.9%) of chemotherapy of chemotherapy requests contain clear diagnosis, 93.7% of them contain clear weight, 95.8% of them contain clear surface area, 100% of them have a full regimen table and 98.9% of chemotherapy requests have a clear author's identification as shown in table 4.10 below. Which affect positively on quality of care, patient's health and safety and recovery early. When comparing our findings with a study was done in all departments providing breast cancer services, we found the clear diagnosis 98%, chemotherapy regimen plan is 92% (Eid, 2019), which nearly about the same which we had.

**Table (4.10) percentage of completeness of chemotherapy request form in the medical files of children with cancer in RSPH in the Gaza Strip**

| Items | Not filled | | Completely filled | | Mean | MD | Std |
|---|---|---|---|---|---|---|---|
| | N | % | N | % | | | |
| Clear diagnosis | 2 | 2.1 | 93 | 97.9 | 97.9 | 100.0 | 14.4 |
| Clear weight and height | 6 | 6.3 | 89 | 93.7 | 93.7 | 100.0 | 24.5 |
| Clear body surface area | 4 | 4.2 | 91 | 95.8 | 95.8 | 100.0 | 20.2 |
| Chemotherapy regimen plan | 0 | 0.0 | 95 | 100.0 | 100.0 | 100.0 | 0.0 |
| Author's identification | 1 | 1.1 | 94 | 98.9 | 98.9 | 100 | 10.26 |
| Mean = 97.3, MD = 100 Std= 9.04 | | | | | | | |

The completeness of pediatric cancer characteristics domain plays an essential role in the diagnosis and treatment plan of the patients as seen in the table 4.11.

In general, there is great deficit in documentation of cancer characteristics in patient's file. The majority (72.5%) of medical files that are supposed to talk about cancer behavior do not talk about aggressiveness and metastasis of cancer. 88. 2.6% of files don't show the clear grading of cancer. 86.3% of files don't provide any information about the staging system. This is considered a weak point for the medical files in department of providing pediatric oncology services. documentation of pediatric cancer characteristics domain is not enough and may affect treatment plan and patient safety and the researcher may explain this due to lack of human resources, workload and relying the physicians on the presence histopathology report which may be missing from the file. 62.7% of files that are supposed to contain histopathology report, contain histopathology report and 37.3% of them not contain histopathology report, so this needs more focusing from decision makers to promote the documentation process. When comparing it with medical records of colorectal cancer patients in the main hospitals involved in colorectal cancer management, 84% of medical files don't show the morphology of cancer, 87% of them don't talk about cancer behavior, 97% don't talk about cancer grade and 96% of medical files don't show a clear cancer stage (Wehedi, 2019). The total of medical files completeness mean is 59.99 with SD 12.1 as shown in table 4.12. The majority of key informants attributed the incompleteness of medical files to the shortage of staff, workload and movement of patients from a service to another holding their files with absence of electronic medical files and networking these files. A Key informant said '*Sometimes the parents, especially women, don't realize that they should take a report on their children from the hospital to which the child is referred abroad to clarify the condition of their child and put it in the child's file, and it is possible that the doctor himself does not care to ask about such papers. It is possible for parents to obtain the required reports but they do not know the value of these reports and do not bring them to the doctor who treats the child in the RSPH*'.

**Table (4.11) percentage of completeness of cancer related factors in the medical files of children with cancer in RSPH in the Gaza Strip**

| Items | Not filled | | Complete | | Mean | MD | Std |
|---|---|---|---|---|---|---|---|
| | N | % | N | % | | | |
| Cancer morphology | 19 | 37.3 | 32 | 62.7 | 62.75 | 100 | 48.83 |
| Cancer behavior | 37 | 72.5 | 14 | 27.5 | 27.45 | 0.0 | 45.07 |
| Cancer grade | 45 | 88.2 | 6 | 11.8 | 11.76 | 0.0 | 32.54 |
| Cancer stage | 44 | 86.3 | 7 | 13.7 | 13.73 | 0.0 | 34.75 |
| Mean = 28.92, MD = 25.0, Std= 28.88 | | | | | | | |

**Table (4.12) Mean of completeness of the medical files of children with cancer in RSPH in the Gaza Strip**

| Item | Mean | MD | Std |
|---|---|---|---|
| Patient identification | 87.65 | 90.00 | 14.85 |
| Patient biographical data | 51.63 | 52.00 | 16.38 |
| Medical record characteristic | 70.1 | 72.1 | 12.52 |
| Medication Record | 40.8 | 50.00 | 19.36 |
| The history and physical exam | 53. 3 | 66.67 | 34.99 |
| Chemotherapy record | 97.3 | 100 | 9.04 |
| Cancer related characteristics | 28.92 | 25.00 | 28.88 |
| **Total** | 59.99 | 62.9 | 12.1 |

A consultant oncologist said '*Sometimes we couldn't know the full story of pediatric with cancer, we don't know if he takes chemotherapy or radiotherapy, if he is referred or not. Patients could be responsible for the loss some contents such as lab tests and radiological examinations when taken during travel*'.

It is appeared from the results of both qualitative and quantitative data results that the completeness of medical records about 60%. The completeness of medication record and cancer related characteristics is low and this may be due to workload, shortage of staff and the caregivers of children with cancer, and medical staff were not aware about the important of medical records completeness and its key role in quality of care and follow up.

### 4.2.11 Accessibility

**Physical accessibility of pediatric cancer services**

As shown in table 4.13, There are 42.9% of patients suffer from the difficulty in reaching the hospital. That may be due to the long distance or the high transportation cost or both. This finding is consistent with Skaik (2013) study, in which about 36.3% of participant suffering somewhat difficulty in reaching the oncology departments and out-patient daily care of the cancer clinics in three hospitals (Al-Shifa, European Gaza Hospitals and RSPH).

According to the American Hospital Association (2017), 3.6 million people in the United States don't have access to medical care because transportation problems as lack of vehicle access, insufficient infrastructure, long distances and long times of access to required services, transportation costs and counter policies that influence travel. Transportation problems can influence a person's access to health care services. These barriers can lead to missed or delayed health care dates, increased health expenses and overall poor health outcomes.

**Table (4.13) Distribution of the study participants according to their perspectives about physical accessibility and waiting time**

| Items | N | % |
|---|---|---|
| **Access to hospital is easy** | | |
| Yes | 120 | 57.1 |
| No | 90 | 42.9 |
| **Total** | **210** | **100.0** |
| **Generally, the number of minutes you wait to receive the children cancer the services from the hospital** | | |
| 60 and less | 81 | 38.6 |
| 61 to 120 | 61 | 29.0 |
| More than 120 | 68 | 32.4 |
| **Total** | **210** | **100.0** |
| **Mean = 116.7, MD = 120.00, Std = 82.86** | | |
| **From your point of view, the time consumed is** | | |
| Reasonable | 133 | 63.3 |
| Lengthy | 61 | 29.0 |
| Short | 16 | 7.6 |
| **Total** | **210** | **100.0** |
| **The waiting time was long before chemotherapy session** | | |
| Yes | 19 | 11.9 |
| to some extent | 22 | 13.8 |
| No | 119 | 74.4 |
| **Total** | **160** | **100.0** |

*Table (4.13a): Continued*

| | | |
|---|---|---|
| **In case of hospital visit for a follow-up, the waiting time to see the doctor is long** | | |
| Yes | 54 | 25.7 |
| to some extent | 70 | 33.3 |
| No | 86 | 41.0 |
| **Total** | **210** | **100.0** |
| **The waiting time to get the lab services is long** | | |
| Yes | 40 | 19.2 |
| To some extent | 46 | 22.1 |
| No | 122 | 58.7 |
| **Total** | **208** | **100.0** |
| **Staying long time until receiving medications by nurses** | | |
| Yes | 6 | 3.1 |
| to some extent | 14 | 7.2 |
| No | 175 | 89.7 |
| **Total** | **195** | **100.0** |
| **Average waiting time in the external hall (min** | | |
| <30 | 77 | 36.7 |
| 30-60 | 75 | 35.7 |
| >60 | 58 | 27.6 |
| **Total** | **210** | **100.0** |
| **The waiting time to get the pharmacy services is long** | | |
| Yes | 2 | 1.3 |
| To some extent | 8 | 5.2 |
| No | 145 | 93.5 |
| **Total** | **155** | **100.0** |

**-Time accessibility of pediatric cancer services**

Generally, the mean of waiting time to receive the children cancer services from entry to the RSPH to exit from it was 116.7 mins as shown in table 4.13, 38.6% of participants spent 60 minutes or less, 29.0% spent between 60 and 120 minutes and 32.4% spent more than 120 minutes. Despite this, 63.3% of participant thought the waiting time is reasonable and 29% thought that waiting time is lengthy. It was found that 37.7% of participants did wait less than 30 minutes before entering the doctor's room and 63.3% of participants did wait 30 minutes or more. A nurse said when asked about waiting time '*I see that there is not enough contact time with the doctor due to the large number of cases, so I expect there is no a long waiting time'.*

**-Evaluation of Referral**

**Table (4.14) Distribution of the study participants according to their perspectives about external referral**

| | | |
|---|---|---|
| **Experiencing referral to outside** | | |
| Yes | 190 | 90.5 |
| No | 20 | 9.5 |
| **Total** | **210** | **100.0** |
| **The child usually has difficulty attaining permit for that** | | |
| Yes | 78 | 41.1 |
| To some extent | 25 | 13.2 |
| No | 87 | 45.8 |
| **Total** | **190** | **100.0** |
| **Better service at this hospital than outside** | | |
| Yes | 25 | 13.2 |
| To some extent | 53 | 27.9 |
| No | 94 | 49.5 |
| I don't Know | 18 | 9.5 |
| **Total** | **190** | **100.0** |
| **Preferring treatment outside Gaza** | | |
| Yes | 99 | 52.1 |
| To some extent | 29 | 15.3 |
| No | 62 | 32.6 |
| **Total** | **190** | **100.0** |
| **Referral is being done due to lack of service** | | |
| Yes | 173 | 91.1 |
| To some extent | 9 | 4.7 |
| No | 8 | 4.2 |
| **Total** | **190** | **100.0** |
| **The permit request to refer the child abroad via Erez refused before that** | | |
| Yes | 48 | 25.3 |
| No | 142 | 74.7 |
| **Total** | **190** | **100.0** |
| **The number of times the transfer request was rejected** | | |
| Once | 20 | 47.9 |
| Twice | 15 | 31.3 |
| Three | 10 | 20.8 |
| **Total** | **48** | **100.0** |
| **Mean = 1.73, MD = 2.00, Std = 0.79** | | |

As shown in table 4.14, 90% of children with cancer were experiencing referrals abroad. Skaik (2013) reported 72.5% of patients were experiencing referral abroad. The study revealed that *49.5%* of Patient's caregivers reported that the services at hospitals abroad were better than the local ones and that is compatible with Skaik (2013) result, which

showed 44.3% of patients reported the services at hospitals abroad were better than than in the local hospitals. As in table 4.14, 41.1% of children have difficulty in attaining permits for referral**.** 52.1% of study participants preferred their children treatment abroad and this compatible with that more than half of the referred cancer patients (52.7%) preferred treatment abroad (Skaik, 2013). It was found that 91.1% of caregivers reported that referrals were primarily due to lack of services locally and 25.3% of requests to transfer the children abroad via Erez refused once or twice or more**.**

A consultant doctor commented on permits as he said *'Sometimes there is a refusal for the accompanying person permit, sometimes there is a refusal for both the accompanying person and child permits together, and in some cases the application is under auditing and it takes time. The issue of permit is more difficult than referral and the most of permit problems are due to the accompanying person not due to of the child*'.

The researcher believed that referral abroad is somewhat difficult and expensive due to bad economic and political situation in the Gaza strip. In addition to that, patients with cancer are exhausted and suffer from long-term complications that burden their movement. The key informant when asked about referral abroad commented that '*Patients are referred for medicinal reasons (chemotherapy, immunotherapy), diagnosis, radiotherapy, surgery and bone marrow transplant. Child referrals are always given a priority, they are done directly and the child is referred for a specific and clear goal. There is no long waiting time to refer the child abroad that lead to earlier diagnosis, faster treatment, a lower risk of complications. the child's is referred due to a lack of chemotherapy very little because the PCRF provides most of the chemotherapy in corporation with MOH. Most of referrals are due to immunotherapy or diagnostic reasons*'. And the head of the nursing department said '*Most of the cases went to the West Bank and Jerusalem, there are a few cases they are referred to the occupied lands who went by favoritism due to their therapies are not available in the West Bank and Jerusalem and their condition is difficult*'.

A consultant hematologist who works in providing of oncology services when asked about referral commented that 'T*here are patients in isolation in RSPH and we are afraid to refer them due to the fear from any infection, but we feel reassured about our patients when they are referred abroad due to availability of advanced diagnostic tools and surgeons who specialize in pediatric tumors abroad, and the surgery operation is usually accompanied by radiation that is not available in Gaza*'.

In conclusion, most of children caregivers think the waiting time is reasonable, but nearly more than a third of caregivers suffer from the difficulty in reaching the hospital. Most of the children with cancer are referred due to diagnostic reasons or immunotherapy, there are cases referred due to surgery, radiotherapy and little cases are referred due to chemotherapy and bone marrow transplantation. In general, child referrals are always given a priority and there is no long waiting time to refer the child, but in many cases the problem is with accompanying person's permit or with the permits of both accompanying person and the child.

**Table (4.15) The barriers facing pediatric with cancer to receive pediatric health services**

| **The main challenges/barriers you face with regard to services that the child receives from this hospital** | | |
|---|---|---|
| Lack of specialized or diagnostic services | 181 | 86.2 |
| Limited availability of therapy ways | 88 | 41.9 |
| Long waiting time | 81 | 38.6 |
| Crowdedness of the hospital | 57 | 27.1 |
| Short contact time with the provider | 23 | 11.0 |
| Poor staff communication | 10 | 4.8 |
| Infrequent appointments | 4 | 1.9 |
| Infrequent lab. Analysis | 2 | 1.0 |
| **In the past year, you are returned home without receiving the services the child came to receive** | | |
| Yes | 33 | 15.7 |
| No | 177 | 84.3 |
| **Total** | **210** | **100.0** |
| **If yes, indicate why** | | |
| Un-available of Chemotherapy | 23 | 69.7 |
| Immunity Decrease | 4 | 12.1 |
| Others | 6 | 18.2 |
| **Total** | **33** | **100.0** |
| **The number of times the child has returned home without receiving the needed services** | | |
| Once | 13 | 39.4 |
| Twice | 15 | 45.5 |
| Three and more | 5 | 15.1 |
| **Total** | **33** | **100.0** |

The most frequent obstacles to receiving pediatric cancer services in RSPH as mentioned in figure 4.3, were Lack of specialized and diagnostic services as reported by 86.2% of study participants, followed by Limited availability of therapy ways as reported by 41.9%, then long waiting time as indicated by 38.6%. This is somewhat consistent with previous results in which 63.3% of study participants did perceive the total spent time to receive

pediatric cancer services as reasonable and 29% did perceive the total spent time as lengthy` and that somewhat is consistent with Skaik (2013) study, around 28.7% of patients reported that the waiting time was long at the physician. Every aspect of the patient experience-specifically trust in the caregiver and perceived quality of care negatively correlated with longer waiting times (Bleustein & et al, 2014). Nearly 15% of children with cancer were returned at least one in the past year without receiving services they came to receive.

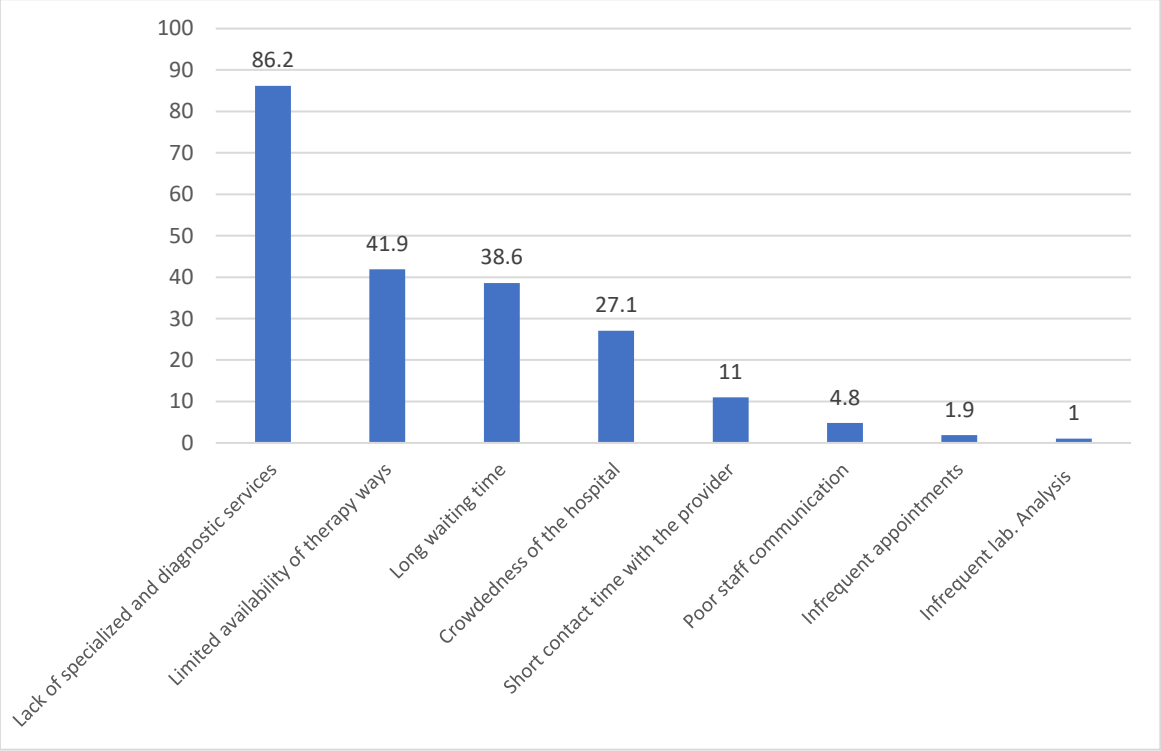


**Figure 4.3: The main barriers to receive services from RSPH**

### 4.2.12 Coordination

As shown in table 4.16, most of participants expressed their satisfaction about cooperation between the staff with a mean of 85%.

A consultant oncologist when asked about coordination explained that "The relationship between the staff in RSPH is based on respect, there are coordination and cooperation between the staff, everyone knows their task, any of the service providers can inquire about any matter from another service provider without obstacles. But the problem with internal referral to other hospital in Gaza". And he added '*The internal referral for imaging test is*

*difficult than for surgery. In surgery referral, it is possible to coordinate with the surgeon by telephone*'.

The head of nursing department commented on the coordination as he said *'There is difficulty in internal referral, we should call the ambulance station because we don't have an ambulance in RSPH and if one of us goes with the child, the staff in Al-Shifa hospital deal with him badly. Sometimes the specialist is not present and they did not put the patient in a suitable place. Moreover, I have to send someone from the medical team with the case even though there are not enough number of staff in the department'.* On the contrary, the key informant said *' In case of internal referral, the seriousness of cancer is taken into consideration and they are given close appointments, especially with children with cases'.*

### 4.2.13 User-provider interaction

**Table (4.16) Distribution of the study participants according to their interaction with provider**

| | | Strongly disagree | disagree | Neutral | Agree | Strongly Agree | Weighted Mean |
|---|---|---|---|---|---|---|---|
| The doctor deals with patients and their caregivers in a friendly way | N | 1 | 11 | 22 | 103 | 73 | 82.5 |
| | % | 0.5 | 5.2 | 10.5 | 49.0 | 34.8 | |
| The doctor pay attention to the beliefs and emotions of patients and their caregivers | N | 4 | 20 | 19 | 96 | 71 | 80.0 |
| | % | 1.9 | 9.5 | 9.0 | 45.7 | 33.8 | |
| During visiting, you allowed to say everything that you think is important without interruption | N | 2 | 15 | 17 | 92 | 84 | 83.0 |
| | % | 1.0 | 7.1 | 8.1 | 43.8 | 40.0 | |
| The doctor listens carefully to everything you say during consultation | N | 4 | 15 | 16 | 95 | 80 | 82.0 |
| | % | 1.9 | 7.1 | 7.6 | 45.2 | 38.1 | |
| If you have some questions of a medical nature, you can contact a doctor without problems | N | 9 | 12 | 38 | 65 | 86 | 79.7 |
| | % | 4.3 | 5.7 | 18.1 | 31.0 | 41.0 | |
| You feel that the doctor understands you | N | 3 | 8 | 17 | 119 | 63 | 82.0 |
| | % | 1.4 | 3.8 | 8.1 | 56.7 | 30.0 | |
| It is easy to understand what the doctor said | N | 0 | 11 | 28 | 103 | 68 | 81.7 |
| | % | 0.0 | 5.2 | 13.3 | 49.0 | 32.4 | |
| The doctor made sure that you understood his explanations and instructions | N | 1 | 14 | 25 | 111 | 59 | 80.3 |
| | % | 0.5 | 6.7 | 11.9 | 52.9 | 28.1 | |
| The doctor examined the child patient with cancer thoroughly | N | 4 | 8 | 14 | 100 | 84 | 84.0 |
| | % | 1.9 | 3.8 | 6.7 | 47.6 | 40.0 | |
| The doctor responds to all your questions, requests and concerns | N | 1 | 17 | 16 | 113 | 63 | 81.0 |
| | % | 0.5 | 8.1 | 7.6 | 53.8 | 30.0 | |
| The doctor always willing to help you | N | 1 | 13 | 24 | 99 | 73 | 81.9 |
| | % | 0.5 | 6.2 | 11.4 | 47.1 | 34.8 | |
| In Many times the doctors use a | N | 59 | 100 | 18 | 30 | 3 | 42.6 |

| | | Strongly disagree | disagree | Neutral | Agree | Strongly Agree | Weighted Mean |
|---|---|---|---|---|---|---|---|
| language difficult for you to understand without adequate explanation | % | 28.1 | 47.6 | 8.6 | 14.3 | 1.4 | |
| The doctor explained the advantages and disadvantages of the treatment or care strategy | N. | 9 | 30 | 24 | 85 | 62 | 75.3 |
| | % | 4.3 | 14.3 | 11.4 | 40.5 | 29.5 | |
| You think the doctor told the whole truth | N | 4 | 16 | 6 | 81 | 103 | 85.0 |
| | % | 1.9 | 7.6 | 2.9 | 38.6 | 49.0 | |
| The doctor involved you in the decision-making | N | 11 | 27 | 35 | 100 | 37 | 71.9 |
| | % | 5.2 | 12.9 | 16.7 | 47.6 | 17.6 | |
| In your opinion, the doctor had a reassuring attitude and way of thinking | N | 4 | 11 | 22 | 118 | 55 | 79.9 |
| | % | 1.9 | 5.2 | 10.5 | 56.2 | 26.2 | |
| The doctor respect patient's appointments | N | 1 | 6 | 10 | 100 | 93 | 86.5 |
| | % | 0.5 | 2.9 | 4.9 | 47.6 | 44.3 | |
| the doctor informs you when to come for the next follow-up | N. | 0 | 1 | 1 | 69 | 139 | 93.0 |
| | % | 0.0 | 0.5 | 0.5 | 32.9 | 66.2 | |
| At emergency, it is easy to contact the doctor | N | 6 | 10 | 23 | 85 | 81 | 82.0 |
| | % | 2.9 | 4.9 | 11.2 | 41.5 | 39.5 | |
| Secretaries are courteous, knowledgeable, helpful, and attentive to your needs | N | 1 | 1 | 9 | 89 | 110 | 89.1 |
| | % | 0.5 | 0.5 | 4.3 | 42.4 | 52.4 | |
| The nurse deals with patients and their caregivers in a friendly way | N | 0 | 1 | 8 | 75 | 125 | 91.0 |
| | % | 0.0 | 0.5 | 3.8 | 35.9 | 59.8 | |
| Nurses are courteous, knowledgeable, helpful, and attentive to your needs | N | 0 | 0 | 7 | 79 | 123 | 91.1 |
| | % | 0.0 | 0.0 | 3.3 | 37.8 | 58.9 | |
| The nurse never too busy to respond to your request | N | 0 | 2 | 12 | 91 | 104 | 88.4 |
| | % | 0.0 | 1.0 | 5.7 | 43.5 | 49.8 | |
| The nurse follows the child carefully while you are receiving chemotherapy | N | 0 | 2 | 7 | 92 | 98 | 88.7 |
| | % | 0.0 | 1.0 | 3.5 | 46.2 | 49.5 | |
| You feel that the nurse deals with patients fairly | N | 1 | 2 | 12 | 83 | 110 | 88.8 |
| | % | 0.5 | 1.0 | 5.7 | 39.9 | 52.9 | |
| The nurse provides advice and guidance about the treatment the child is receiving | N | 4 | 9 | 24 | 83 | 85 | 83.0 |
| | % | 2.0 | 4.4 | 11.7 | 40.5 | 41.5 | |
| the pharmacist deals with you respectfully | N | 0 | 1 | 4 | 64 | 89 | 90.5 |
| | % | 0.0 | 0.6 | 2.5 | 40.5 | 56.3 | |
| It is easy to ask pharmacist anything about the medications | N | 0 | 2 | 7 | 67 | 82 | 89.0 |
| | % | 0.0 | 1.3 | 4.4 | 42.4 | 5.9 | |
| the pharmacist informs you how to give the child his medication every visit | N | 0 | 3 | 2 | 50 | 103 | 92.0 |
| | % | 0.0 | 1.9 | 1.3 | 31.6 | 65.2 | |
| There is good cooperation between the staff | N | 0 | 5 | 14 | 113 | 76 | 85.0 |
| | % | 0.0 | 2.4 | 6.7 | 54.3 | 36.2 | |
| Mean = 81.7 , MD = 81.3 , Std = 10.5 | | | | | | | |

As shown in table 4.16, most participants expressed their satisfaction about patient-provider interaction with children cancer services with a mean of 81.7and SD 10.5

The higher mean of user- doctor interaction was the doctor inform caregiver when the child to come for the next follow-up with the mean of 93%. On the other hand, the lowest mean

of user- doctor interaction was the doctor involved child's caregiver in the decision-making with the mean 71.9%. A consultant Oncologist commented on this by saying '*We don't always involve the caregivers of children diagnosed with cancer in the decision making due to we know the patient's interest and what is appropriate for them more than anyone, especially when it comes to a serious disease like cancer*'.

The higher mean of user-nurse interaction was the nurses are courteous, knowledgeable, helpful, and attentive to patients and their caregivers needs with a mean of 91.1%. On the other hand, the lowest mean of user- nurse interaction was the nurse provide advice and guidance about the treatment the child is receiving with a mean of 83%

The higher mean of user-pharmacist interaction was the pharmacist inform caregivers how to give their children his medication every visit with a mean of 92%. *The Pharmacist commented on this by saying 'My work as pharmacist requires me not only to dispense the medications, but also to give instructions during dispensing medications and inform the patient every time how to take these medicines'.* On the other hand, the lowest mean of user- pharmacist interaction was if caregiver of child wants to ask pharmacist anything about the medications, they find it easy with a mean of 89%.

As shown in table 4.16, about 82% of caregivers showed that it was easy to contact with the physician at emergencies and that is inconsistent with Skaik (2013) study which revealed About 65.2% of patients showed that it was not easy to contact with the physician at emergencies.

### 4.2.14 Follow up

As shown in table 4.17, In the pediatric hematology and oncology department, most of participants expressed their agreement that the doctor informs them when to come for the next follow-up with a mean of 93%. The majority of pediatric caregivers (98.1%) had adherence to clinic appointments and follow up to avoid delaying of their children treatment as mentioned in table 4.17. These results are consistent with Skaik (2013) study, in which that 99.2% of patients showed that health care providers arranged appointments for them, (98.4%) of them had adherence to clinic appointments and follow up. On other hand, in results we had the doctor respect patient's appointments with a mean of 85.6% and the average total number of follow up visits per year is 24. A consultant oncologists reported '*Weekly, we receive nearly 70 cases of children with cancer in addition to cases*

*of different blood disease. but we don't have the real number of children with cancer due to we count the number of visits, not the number of cases*'.

**Table (4.17) Distribution of the children with cancer according to their follow-up**

| Items | No. | % |
|---|---|---|
| **Conducting follow up visits regularly** | | |
| Yes | 206 | 98.1 |
| No (Covid-19) | 4 | 1.9 |
| **Total** | **210** | **100.0** |
| **Number of follow-up visits per year** | | |
| Less than 5 | 65 | 31.0 |
| From 5 to 15 | 77 | 36.6 |
| Above 15 | 68 | 32.4 |
| **Total** | **210** | **100.0** |
| **Mean = 24.03, MD = 12.0, Std = 39.68** | | |
| **Follow-up visits number are adequate** | | |
| Yes | 192 | 91.4 |
| to some extent | 14 | 6.7 |
| No | 4 | 1.9 |
| **Total** | **210** | **100.0** |
| **You have been approached by provider because the child did not follow up regularly** | | |
| Yes | 57 | 45.6 |
| No | 68 | 54.4 |
| **Total** | **125** | **100.0** |
| **The child patient with cancer underwent a medical imaging in the previous year** | | |
| Yes | 136 | 65.4 |
| No | 72 | 34.6 |
| **Total** | **208** | **100.0** |
| **Interval since the medical imaging test** | | |
| Less than 2 | 49 | 36.02 |
| From 2 to 5 | 56 | 41.18 |
| Above 5 | 31 | 22.8 |
| **Total** | **136** | **100.0** |
| **Receiving feedback about that medical imaging test** | | |
| Yes | 123 | 90.4 |
| No | 13 | **9.6** |
| **Total** | **136** | **100.0** |
| **The child patient with cancer underwent laboratory analysis in the previous year** | | |
| Yes | 201 | 95.7 |
| No | 9 | 4.3 |
| **Total** | **210** | **100.0** |
| **Receiving feedback about the results of laboratory analysis** | | |
| Yes | 193 | 96.0 |
| No (Back to home without receiving the result) | 8 | 4.0 |
| **Total** | **201** | **100.0** |
| **Doing lab tests at private sites** | | |
| Yes | 42 | 20.0 |
| No | 168 | 80.0 |
| **Total** | **210** | **100.0** |

As shown in table 4.17, 65.4% of children with cancer underwent imaging medical tests in previous year and 90.4% received feedback about these tests. 95.7% of children with

cancer underwent laboratory tests in previous year and 96% received feedback about these tests.

**Table (4.18) Distribution of the study participants according to their perspectives about physician control over chemotherapy side effects and complication**

| Items | No. | % |
|---|---|---|
| **Physician controls the disease** | | |
| Yes | 156 | 74.3 |
| To some extent | 38 | 18.1 |
| No | 16 | 7.6 |
| **Total** | **210** | **100.0** |
| **Physician alert you about side effects of chemotherapy treatment and how to deal with them** | | |
| Yes | 171 | 84.7 |
| To some extent | 17 | 8.4 |
| No | 14 | 6.9 |
| **Total** | **202** | **100.0** |
| **Physician is caring to control complications** | | |
| Yes | 176 | 87.1 |
| To some extent | 20 | 10.0 |
| No | 6 | 3.0 |
| **Total** | **202** | **100.0** |
| **Physician prescribes drugs to control complication** | | |
| Yes | 149 | 73.8 |
| To some extent | 32 | 15.8 |
| No | 21 | 10.4 |
| **Total** | **202** | **100.0** |
| **Physician alert you about side effects of drugs and how to deal with them** | | |
| Yes | 72 | 39.8 |
| To some extent | 56 | 30.9 |
| No | 53 | 29.3 |
| **Total** | **181** | **100.0** |

As shown in table (4.18), The majority of caregivers felt that the physicians are caring to control complications and they prescribed drugs to control it. In Skaik (2013) study, 82.6% of patient felt that the physicians are caring to control complications and 93.7% reported that Physician prescribes drugs to control complication. Physicians control the disease were perceived by 74.3% of caregivers and in Skaik (2013) study by 86.1% of patients.

In conclusion, Majority of children diagnosed with cancer are conducting follow up visits regularly and the doctor respect patient's appointments. This result reflects awareness of caregivers about the importance of conducting follow up regularly.

### 4.2.15 Overall perspectives about services

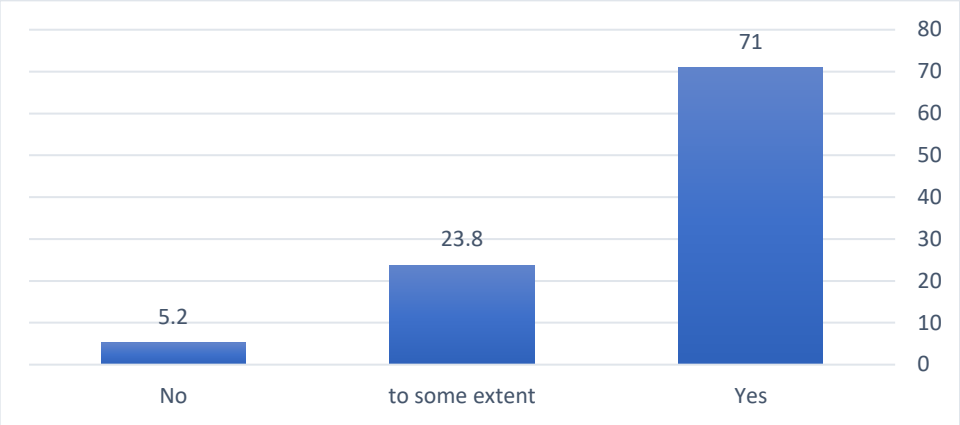


**Figure 4.4 In general, the cancer health services that your child has received meet your expectation**

As shown in figure 4.4, in general, 71.0% of caregivers reported that the cancer health services that your child has received meet your expectation and about 5% reported the cancer health services not meet your expectation. For overall caregiver's satisfaction about their child's health status, as shown in figure 4.5, *51.4%* of caregivers were satisfied, 22.4% of caregivers were highly satisfied about their children health status. This is consistent with Skaik (2013), in which 78.3% were satisfied about their health. The results we had revealed more patients' caregiver perceptions rather than their children actual health status and the researcher assumes that caregiver's perspectives are linked to their expectations and they are not sure whether caregivers know the type of service being provided or that feeling could be related to their religious beliefs of accepting the realities as it is outside their control from Allah".

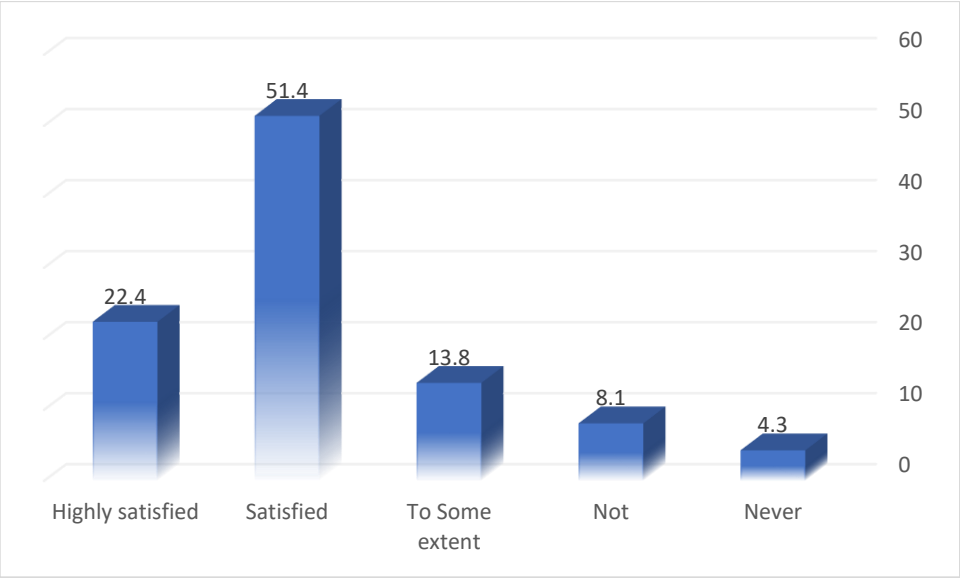


**Figure 4.5 In general, the satisfaction about the child's health status**

**Table (4.19) Distribution of the study participants according to their satisfaction**

| Items | | Strongly disagree | disagree | Neutral | Agree | Strongly Agree | Weighted Mean |
|---|---|---|---|---|---|---|---|
| The service providers are well dressed and appear neat | N | 1 | 0 | 2 | 79 | 127 | 91.7 |
| | % | 0.5 | 0.0 | 1.0 | 37.8 | 60.8 | |
| Hospital environment is comfortable (cleanliness, space, quiet and so on) | N | 0 | 0 | 3 | 86 | 120 | 91.2 |
| | % | 0.0 | 0.0 | 1.4 | 41.1 | 57.4 | |
| The nature of the place is suitable for children | N | 0 | 0 | 2 | 71 | 136 | 92.8 |
| | % | 0.0 | 0.0 | 1.0 | 34.0 | 65.1 | |
| There are enough toilets in hospital | N | 1 | 0 | 6 | 91 | 111 | 89.8 |
| | % | 0.5 | 0.0 | 2.9 | 43.5 | 53.1 | |
| Hospital toilets are clean | N | 0 | 0 | 3 | 79 | 127 | 91.9 |
| | % | 0.0 | 0.0 | 1.4 | 37.6 | 60.8 | |
| The hospital is equipped with modern and up-to date equipment | N | 1 | 2 | 13 | 85 | 108 | 88.4 |
| | % | 0.5 | 1.0 | 6.2 | 40.7 | 51.7 | |
| The hospital operating hours are convenient to you | N | 0 | 2 | 9 | 107 | 91 | 87.5 |
| | % | 0.0 | 1.0 | 4.3 | 51.2 | 43.5 | |
| Booking an appointment is easy | N | 0 | 4 | 6 | 99 | 98 | 88.1 |
| | % | 0.0 | 1.9 | 2.9 | 47.8 | 47.3 | |
| Waiting time is long | N | 24 | 62 | 45 | 52 | 26 | 59.4 |
| | % | 11.5 | 29.7 | 21.5 | 24.9 | 12.4 | |
| Satisfaction about Welcoming and greeting of service providers | N | 2 | 6 | 15 | 115 | 71 | 83.6 |
| | % | 1.0 | 2.9 | 7.2 | 55.0 | 34.0 | |

***Table (4.19a): Continued***

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| The staff collaborate with patients | N | 1 | 2 | 6 | 120 | 80 | 86.4 |
| | % | 0.5 | 1.0 | 2.9 | 57.4 | 38.3 | |
| The time that the health providers spent with patient is enough | N | 5 | 12 | 24 | 102 | 66 | 80.3 |
| | % | 2.4 | 5.7 | 11.4 | 48.8 | 31.6 | |
| Having difficulty attaining referrals for medical imaging tests | N | 77 | 68 | 13 | 7 | 6 | 36.3 |
| | % | 45.0 | 39.8 | 7.6 | 3.3 | 3.5 | |
| Having easy access to the specialists your child is needing | N | 2 | 8 | 11 | 112 | 76 | 84.1 |
| | % | 1.0 | 3.8 | 5.3 | 53.6 | 36.4 | |
| Some of the doctors you have seen lack experience with child medical problems | N | 64 | 103 | 18 | 16 | 8 | 41.0 |
| | % | 30.6 | 49.3 | 8.6 | 7.7 | 3.8 | |
| The services providers respect of patient privacy | N | 1 | 0 | 5 | 89 | 114 | 90.1 |
| | % | 0.5 | 0.0 | 2.4 | 42.6 | 54.5 | |
| The medical care that the child patient with cancer has been receiving is just about perfect | N | 1 | 8 | 32 | 102 | 66 | 81.4 |
| | % | 0.5 | 3.8 | 15.3 | 48.8 | 31.6 | |
| The doctors are good about explaining the reason for medical test | N | 3 | 8 | 11 | 125 | 62 | 82.5 |
| | % | 1.4 | 3.8 | 5.3 | 59.8 | 29.7 | |
| The way services providers tell you about improving the child health | N | 2 | 6 | 25 | 116 | 60 | 81.6 |
| | % | 1.0 | 2.9 | 12.0 | 55.5 | 28.7 | |
| When the child undergoes a medical examination, you are sure that everything is checked and examined the doctors are doing their best to prevent you from worrying unnecessarily | N | 3 | 4 | 14 | 116 | 72 | 83.9 |
| | % | 1.4 | 1.9 | 6.7 | 55.5 | 34.4 | |
| Having enough information about the disease | N | 4 | 11 | 11 | 120 | 63 | 81.7 |
| | % | 1.9 | 5.3 | 5.3 | 57.1 | 30.0 | |
| Satisfaction about medical care that the child is receiving | N | 2 | 4 | 25 | 110 | 68 | 82.8 |
| | % | 1.0 | 1.9 | 12.0 | 52.6 | 32.5 | |
| Visiting hours are very comfortable | N | 6 | 11 | 43 | 117 | 32 | 75.1 |
| | % | 2.9 | 5.3 | 20.6 | 56.0 | 15.3 | |
| The human resources are adequate in number | N | 5 | 26 | 53 | 105 | 19 | 70.3 |
| | % | 2.4 | 12.5 | 25.2 | 50.5 | 9.1 | |
| The available human resources have the needed qualifications | N | 1 | 6 | 27 | 117 | 57 | 81.4 |
| | % | 0.5 | 2.9 | 13.0 | 56.3 | 27.4 | |
| **Mean = 81.4, MD = 80.0, Std = 6.95** | | | | | | | |

As shown in table 4.19, most participants expressed their satisfaction with the children cancer services, with a mean of 81.4 and SD 6.95. In Skaik (2013) study, conducted at the oncology departments and out-patient daily care of cancer clinics in (Al-Shifa, European

Gaza hospitals and RSBH), 91.2% of participants expressed their satisfaction about the provided services.

In the satisfaction domain, the most satisfying issue for the participants was the nature of the place is suitable for children with a mean of 92.8% and the lowest satisfaction issue was human resources are adequate in number with a mean of 70.3%. Regarding privacy, the study is consistent with Skaik (2013) which recorded the privacy with a physician was 90% as perceived by patients. Majority (80.3%) of participants reported the time that the health provider spent with them is enough. This is contrary to what the nurse explained where she said '*The contact with doctors is short because in many times patients come to us to inquire about some things that the doctor didn't explain'.*

### 4.2.16 Emotional and behavioral problems

SDQ version includes 25 items, divided in the domains of Emotional Problems, Conduct Problems, Hyperactivity, Peer Problems and Pro-social domain, 14 from items describe perceived difficulties, 10 perceived strengths and one is neutral. Standard values used for coding responses of perceived difficulties items are 0 (not true), 1 (somewhat true), 2 (certainly true). Five perceived strengths items responses (excluding the pro-social items) are reversely scored, 2 (not true), 1 (somewhat true), 0 (certainly true).

**Table (4.20) psychological adjustment of children with cancer as evaluated by the SDQ tool**

| **Domains** | **Normal** | | **Borderline** | | **Abnormal** | |
|---|---|---|---|---|---|---|
| | **Nu.** | **%** | **Nu.** | **%** | **Nu.** | **%** |
| Emotional | 47 | 28.3 | 20 | 12.0 | 99 | 59.6 |
| Conducted | 54 | 32.5 | 43 | 25.9 | 69 | 41.6` |
| Hyperactivity | 111 | 66.9 | 27 | 16.3 | 28 | 16.9 |
| Peer | 51 | 30.7 | 51 | 30.7 | 64 | 38.6 |
| **Total** | **53** | **31.9** | **30** | **18.1** | **83** | **50.0** |
| Pro-social | 143 | 86.1 | 16 | 9.6 | 7 | 4.2 |

The table 4.20 showed that 59.6% of children have a substantial risk of clinically significant problems in emotional domain (abnormal),12% of children may have clinically significant problems in emotional domain and 28.3% of children have no significant problems in emotional domain (normal). It was found that 41.6% of children have a high risk of clinically significant problems in conducted domain and 38.6% of children have a high risk of clinically significant problems with peer relationship. 50% of children have a substantial risk of clinically significant problems in total difficulties score (emotional,

conducted, hyperactivity and peer), 18.1% of children may have clinically significant problems in total difficulties score, 31.9% of children have no significant problems in total difficulties score.

The study showed the cancer has broad impact on emotional and behavioral aspects of children with cancer so it is assumed there is psycho-oncology services in MOH with treatment and psychological support should be schedule and it is assumed there that there is continuous treatment for children and their families and working collaboratively with local and national and international organizations related to children cancer advocacy, support awareness, research, treatment.

In the study is conducted to evaluate the prevalence of emotional and behavioral problems in Palestinian children with special needs in the Gaza Strip, Using SDQ for parents, the study showed that 38% of children were classified as having psychological issues, 29.1% had emotional issues, 27.8% had conduct issues, 22.8% of them were hyperactive, 41.8% had abnormal peer issues and 6.4% had abnormal pro-social behavior (Thabet, 2017). By using SDQ for teachers, 26.6% of children had psychological issues, 2.5% had emotional issues, 24.1% had conduct issues, 11.4% had hyperactive issues, 21.5% had abnormal peer issues, and 14.1% had abnormal pro-social behavior (Ibid). In the Thabet, Stretch & Vostanis (2000) study was conducted to identify of mental health profiles among children in different ages in the Gaza Strip, the rates of children within clinical range were similar in early childhood (10.9% at age 3, and 11.1% at age 6), higher at age 11 (16.3%) and age 16 (12.3%) and 14.2% in total sample. The SDQ was used to measure children and adolescents' psychosocial vulnerabilities aged 3-16 years in the Gaza Strip, 84.69% of adolescents with normal S&D survey score, 6.12% with borderline S&D survey score and 9.18% with abnormal S&D survey score (Pereznieto,2014). The findings of other studies are not consistent with we had due to severity of cancer disease, cancer treatment and their strong influence on children's emotions and behaviours.

This study is congruent with study was done in Rantssi Specialized Pediatric Hospital and European Gaza Hospital to evaluate quality of life among children with cancer in Gaza Strip, which illustrated the total mean percentage of the QOL among Children with Cancer in the Gaza Strip was 52.53% using Pediatric Quality of Life Inventory (Peds QL 4.0 generic core scale) (Salah, Abu Reyala & Al Jerjawy, 2018).

### 4.2.17 Quality of care

All patients in general, and cancer patients in particular, expect to receive a high quality of care. That's needs stakeholders to deliver appropriate services in terms of effectiveness, patient-centeredness, timeliness, efficacy and equity to achieve ever better care (Berwick, 2002)

A consultant oncologist answered when asked about quality of care 'A*fter presence of BCRF the quality of place, services, referral, chemotherapy availability become more better. We have very good services provided to pediatric with cancer*'. A key informant supported the previous saying as he said '*The presence of PCRF and the participation of the Ministry of Health in the success of the goals relieved many of the suffering of children and parents, contributed well to chemotherapy and care after chemotherapy, and reduced the referral system*'. Moreover, A hematologist who works in providing oncology services added that '*In Gaza the care for pediatric oncology is better than in the neighbor countries, and the quality of care will be more excellent with availability all diagnostic tools, all chemotherapy and immunotherapy and an increase the medical workforce*'.

Another Key informant talked about other dimension related to quality of care '*Transportation may be considered easy for people close to RPSH, but it is considered long and expensive for people far from RSPH, due to they come from the far south and far north especially if the patient goes twice or three a week to receive treatment, and it is supposed that there are doctors arriving at the patients' homes*'.

The surgeon said '*I can do all the necessary surgeries for children with cancer in the abdomen and chest area. In the Gaza we can install and remove Port-A-Cath in vascular surgery department*'. Other key informant said '*Our patients suffered from psychological and financial problems, difficulty with referrals, permits and transportation*'.

As concluded from the key informants, the quality of care became better after PCRF support, but there are still shortages in workforce and diagnostic tools, difficulty with referrals, permits as well as psychological problems and financial problems facing the patients and their caregivers.

## 4.3 Inferential analysis

### Differences in user-provider interaction by demographic character

Table 4.21 illustrates the differences among participants in different governorates in relation to user- provider interaction. One-way ANOVA-test was conducted to examine whether there were statistically significant differences among participants in different governorates in relation to user-provider interaction. Although Khan Younis elicited the highest mean (4.22) and middle zone elicited the lowest mean (3.94). One-way ANOVA-test findings showed that there were no statistically significant differences between participants in different governorates in relation to user-provider interaction ($P$=0.171) ($P$>0.05).

**Table (4.21) Differences between: User – provider interaction in relation to demographic data**

| | Demographic Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| **Gender of the child** | Male | 111 | 4.06 | 0.52 | t | -0.676 | 0.500 |
| | Female | 99 | 4.1 | 0.49 | | | |
| **Age** | Less than 5 | 64 | 3.93 | 0.48 | F | 7.105 | 0.001 |
| | From 5 to 9 | 94 | 4.07 | 0.50 | | | |
| | More than 9 | 52 | 4.27 | 0.47 | | | |
| | **Total** | 210 | 4.08 | 0.50 | | | |
| **Governorates** | North | 42 | 3.99 | 0.52 | F | 1.619 | 0.171 |
| | Gaza | 94 | 4.07 | 0.47 | | | |
| | Middle zone | 22 | 3.94 | 0.57 | | | |
| | Khan Younis | 30 | 4.22 | 0.46 | | | |
| | Rafah | 22 | 4.2 | 0.52 | | | |
| | **Total** | 210 | 4.1 | 0.50 | | | |
| **Father's Work** | Yes | 111 | 4.06 | 0.52 | F | 1.711 | 0.183 |
| | No | 95 | 4.08 | 0.47 | | | |
| | Retired | 4 | 4.53 | 0.59 | | | |
| | **Total** | 210 | 4.08 | 0.50 | | | |
| **Mother's Work** | Yes | 13 | 4.09 | 0.51 | t | 0.104 | 0.917 |
| | No | 197 | 4.07 | 0.50 | | | |
| **Income** | No Income | 70 | 4.13 | 0.50 | F | 2.46 | 0.064 |
| | 999 or less | 68 | 3.95 | 0.50 | | | |
| | 1000 to 1999 | 57 | 4.13 | 0.50 | | | |
| | 2000 or more | 15 | 4.24 | 0.44 | | | |
| | **Total** | 210 | 4.08 | 0.50 | | | |
| **Receiving Assistant** | **Yes** | 70 | 4.05 | 0.54 | t | -0.509 | 0.611 |
| | **No** | 140 | 4.09 | 0.48 | | | |

Using One-way ANOVA-test to examine whether there were statistically significant differences between user-provider interaction by father's work. Although the retired fathers elicited the highest mean (4.53), followed by fathers are not working (4.08) then fathers are

working (4.06). ANOVA-test results showed that there were no statistically significant differences between user-provider interaction by father work (*P*= 0.183), this indicates that there is no difference in the expectation between the working father and the non-working father about provider interaction with them, and it also indicates the good interaction of health providers with all caregivers and their children.

The results of One-way ANOVA-test revealed that there were no statistically significant differences between user-provider interaction by different families' level of income (*P*= 0.064) (*P*<0.05). although family with icome 2000 or more elicited the highest mean followed by families with income "1000 to 1999" and with no income.

**-Differences between User-provider interaction by medical data**

**Table (4.22) Differences between User-provider interaction in relation to medical data**

| | **Medical Data** | **N** | **Mean** | **Std** | **Factor** | **Value** | **Sig.** |
|---|---|---|---|---|---|---|---|
| **Diseases degree** | Low | 30 | 3.94 | 0.37 | F | 5.482 | 0.001 |
| | Intermediate | 38 | 4.16 | 0.40 | | | |
| | High | 69 | 3.93 | 0.49 | | | |
| | I Don't Know | 71 | 4.23 | 0.56 | | | |
| | **Total** | **208** | **4.08** | **0.50** | | | |
| **Interval since the diagnosis** | 12 and less | 84 | 4.04 | 0.48 | F | 0.726 | 0.485 |
| | From 13 to 36 | 69 | 4.08 | 0.53 | | | |
| | 37 and more | 57 | 4.14 | O.50 | | | |
| | **Total** | **210** | **4.08** | **0.50** | | | |
| **Suffering from other diseases** | Yes | 15 | 3.89 | 0.52 | t | -1.506 | 0.133 |
| | No | 195 | 4.09 | 0.50 | | | |

As shown in table 4.22, ANOVA-test results showed that there were statistically significant differences between user-provider interaction by child's disease degree (*P*=0.001). In case of children with unknown cancer degree the user-provider interaction elicited the highest mean, followed by in case of children with intermediate cancer degree then children with low cancer degree. Scheffe test (Annex 9) shows that there is significant difference between a pair of means: "low" and "I don't know", *(P*= 0.008) (<0.05) in favor of those who have cancer with unknown degree , there is significant difference between a pair of means: "intermediate" and "high, p = 0.023 (≤0.05) in favor of those who have

cancer with intermediate cancer and there is significant difference between a pair of means: “high” and “I don’t know", (*P*= 0.000) (<0.05) in favor of those who have cancer with unknown degree.

**-Differences in satisfaction by demographic character**

As shown in table 4.23, One -way ANOVA-test was performed to examine if there were significant differences among participants satisfaction by different governorates. Although Khan Younis elicited the highest mean (3.31) and middle zone elicited the lowest mean (3.18). One- way ANOVA-test results showed that there were no statistically significant differences between participants in different governorates with regard to satisfaction. (*P*= 0.309).

**Table (4.23) Differences between patient satisfaction in relation to demographic data**

| | Demographic Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| **Gender** | Male | 111 | 3.25 | 0.28 | t | -0.001 | 0.999 |
| | Female | 98 | 3.25 | 0.82 | | | |
| **Age** | Less than 5 | 63 | 3.22 | 0.26 | F | 2.207 | 0.113 |
| | From 5 to 9 | 94 | 3.24 | 0.30 | | | |
| | More than 9 | 52 | 3.32 | 0.25 | | | |
| | **Total** | 209 | 3.25 | 0.28 | | | |
| **Governorates** | North | 42 | 3.20 | 0.30 | F | 1.208 | 0.309 |
| | Gaza | 93 | 3.27 | 0.27 | | | |
| | Middle zone | 22 | 3.18 | 0.28 | | | |
| | Khan Younis | 30 | 3.31 | 0.26 | | | |
| | Rafah | 22 | 3.29 | 0.26 | | | |
| | **Total** | 209 | 3.25 | 0.28 | | | |
| **Father Work** | Yes | 111 | 3.27 | 0.28 | F | 1.719 | 0.182 |
| | No | 94 | 3.23 | 0.27 | | | |
| | Retired | 4 | 3.46 | 0.32 | | | |
| | **Total** | 209 | 3.25 | 0.28 | | | |
| **Mother Work** | Yes | 13 | 3.20 | 0.21 | t | -0.795 | 0.428 |
| | No | 196 | 3.26 | 0.28 | | | |
| **Income** | No Income | 70 | 3.22 | 0.28 | F | 0.862 | 0.462 |
| | 999 and less | 67 | 3.25 | 0.29 | | | |
| | 1000 to 1999 | 57 | 3.29 | 0.25 | | | |
| | 2000 0r more | 15 | 3.30 | 0.32 | | | |
| | **Total** | 209 | 3.25 | 0.28 | | | |
| **Receiving Assistant** | Yes | 70 | 3.29 | 0.29 | t | 1.143 | 0.254 |
| | No | 139 | 3.24 | 0.27 | | | |

One-way ANOVA-test was conducted to examine whether there were significant differences between participant satisfaction according to father's work. Although the retired fathers elicited the highest mean (3.46), followed by fathers are working (3.27) then fathers are not working (3.23). The results showed that there were no statistically significant differences between participant satisfaction according to father work (*P*= 0.182). This indicates that there is no difference in the expectation between the working father and the non-working father, and also indicates that the level of service is good, which reflects the satisfaction of the caregivers in general.

**- Differences between satisfaction by medical data**

**Table (4.24) Differences between satisfaction in relation to medical data**

| | Medical Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| **Diseases Grade** | Low | 30 | 3.20 | 0.26 | F | 2.781 | 0.042 |
| | Intermediate | 38 | 3.29 | 0.24 | | | |
| | High | 69 | 3.20 | 0.26 | | | |
| | I Don't Know | 70 | 3.31 | 0.31 | | | |
| | **Total** | 207 | 3.25 | 0.28 | | | |
| **Interval since the diagnosis** | 12 and less | 84 | 3.23 | 0.27 | F | 1.943 | 0.146 |
| | From 13 to 36 | 69 | 3.24 | 0.30 | | | |
| | 37 and more | 56 | 3.32 | 0.25 | | | |
| | **Total** | 209 | 3.25 | 0.28 | | | |
| **Suffering from other diseases** | Yes | 15 | 3.19 | 0.28 | t | -1.004 | 0.317 |
| | No | 194 | 3.26 | 0.28 | | | |
| **Type of cancer** | Leukemia | 110 | 3.21 | 0.29 | F | 2.06 | 0.042 |
| | Lymphoma | 24 | 3.39 | 0.29 | | | |
| | Wilms tumor | 23 | 3.29 | 0.22 | | | |
| | Brain | 15 | 3.12 | 0.25 | | | |
| | Neuroblastoma | 15 | 3.34 | 0.25 | | | |
| | Bone | 10 | 3.35 | 0.23 | | | |
| | Germ | 5 | 3.24 | 0.34 | | | |
| | Rhabdosarcoma | 4 | 3.23 | 0.20 | | | |
| | Other | 3 | 3.43 | 0.26 | | | |
| | Total | 210 | 3.25 | 0.28 | | | |

One-ANOVA-test results revealed that there were statistically significant differences between participant satisfaction by disease degrees (*P*= 0.042), as shown in table 4.24. The caregivers of children with unknown cancer degree elicited the highest mean of satisfaction, followed by caregivers of children with intermediate cancer degree then caregivers of children with low and high cancer degrees. Scheffe test (Annex 10) shows

that there is significant difference between a pair of means: “low” and “I don’t know” (*P*= 0.047) (<0.05) in favor of those who have cancer with unknown degree and there is significant difference between a pair of means: “high” and “I don’t know”, (*P*= 0.013) (≤0.05) in favor of those who have cancer with unknown degree.

One-ANOVA-test results showed that there were statistically significant differences in participants satisfaction according to cancer type (*P*= 0.042), Scheffe test (Annex 11) shows where there are statistically significant differences.

**-Differences in total difficulties scores by demographic character**

Annex 12, illustrated differences in total difficulties among children according to gender. T-test was performed to examine whether there were significant differences between male child and female child with regard to total difficulties. The result showed that there were no statistically significant differences between total difficulties scores by gender (*P*=0.946). despite the fact that female had slightly higher scores. Salah, Abu Reyala & Al Jerjawy (2018) study showed that there is no statistically significant difference in the QOL between male and female children with cancer in the Gaza Strip (*P= 0.985)* (p>0.05).

One-way ANOVA-test results showed that there were no statistically significant differences between total difficulties by different age groups (*P*= 0.297) as shown in annex 12, Although the researcher found that mean of age less 5 is the highest (17.91), followed by age 5-9 (16.47) then the age more than 9 (15.75). Salah, Abu Reyala & Al Jerjawy (2018) study showed there is no statistically significant difference in the QOL between different age groups of the children *(P*= 0.359) (*P* >0.05).

One-way ANOVA-test was performed to examine whether there were significant differences among children with cancer in different governorates with regard to total difficulties. One-way ANOVA-test results revealed that there were no statistically significant differences between total difficulties for children by different governorates (*P*= 0.107) (*P*>0.05) as shown in annex 12 , Although there were statistically significant differences between children’s peer difficulties according to different governorates (*P*= 0.016) (*P* <0.05).

**Table (4.25) Differences between total difficulties in relation to demographic data**

| | Demographic Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| **Father Work** | | | | | | | |
| **Emotional** | Yes | 91 | 4.51 | 2.18 | F | 7.443 | 0.001 |
| | No | 71 | 5.89 | 2.67 | | | |
| | Retired | 4 | 3.50 | 2.38 | | | |
| | **Total** | 166 | 5.07 | 2.50 | | | |
| **Conducted** | Yes | 91 | 3.15 | 1.50 | F | 2.810 | 0.063 |
| | No | 71 | 3.61 | 1.54 | | | |
| | Retired | 4 | 2.25 | 0.96 | | | |
| | **Total** | 166 | 3.33 | 1.53 | | | |
| **Hyperactivity** | Yes | 91 | 4.40 | 1.68 | F | 6.488 | 0.002 |
| | No | 71 | 5.30 | 1.61 | | | |
| | Retired | 4 | 4.00 | 0.82 | | | |
| | **Total** | 166 | 4.77 | 1.69 | | | |
| **Peer** | Yes | 91 | 3.07 | 1.25 | F | 2.220 | 0.112 |
| | No | 71 | 3.55 | 1.73 | | | |
| | Retired | 4 | 3.00 | 0.82 | | | |
| | **Total** | 166 | 3.27 | 1.48 | | | |
| **Prosocial** | Yes | 91 | 7.71 | 1.90 | F | 1.217 | 0.299 |
| | No | 71 | 7.28 | 1.81 | | | |
| | Retired | 4 | 8.00 | 1.41 | | | |
| | **Total** | 166 | 7.54 | 1.85 | | | |
| **Total difficulties (Emotional+ conduct+ hyperactivity+ peer)** | Yes | 91 | 15.12 | 4.93 | F | 8.648 | 0.000 |
| | No | 71 | 18.34 | 5.59 | | | |
| | Retired | 4 | 12.75 | 3.77 | | | |
| | **Total** | 166 | 16.44 | 5.44 | | | |
| **Income** | | | | | | | |
| **Emotional** | No Income | 53 | 5.94 | 2.45 | F | 2.764 | 0.044 |
| | 999 and less | 50 | 5.72 | 2.17 | | | |
| | 1000 to 1999 | 48 | 3.88 | 2.42 | | | |
| | 2000 or more | 15 | 3.67 | 1.95 | | | |
| | **Total** | 166 | 5.07 | 2.50 | | | |
| **Conducted** | No Income | 53 | 3.58 | 1.55 | F | 9.892 | 0.000 |
| | 999 and less | 50 | 3.48 | 1.62 | | | |
| | 1000 to 1999 | 48 | 3.17 | 1.43 | | | |
| | 2000 or more | 15 | 2.40 | 1.12 | | | |
| | **Total** | 166 | 3.33 | 1.53 | | | |
| **Hyperactivity** | No Income | 53 | 5.00 | 1.62 | F | 3.214 | 0.024 |
| | 999 and less | 50 | 5.12 | 1.76 | | | |
| | 1000 to 1999 | 48 | 4.44 | 1.64 | | | |
| | 2000 or more | 15 | 3.87 | 1.51 | | | |
| | **Total** | 166 | 4.77 | 1.69 | | | |
| **Peer** | No Income | 53 | 3.70 | 1.58 | F | 3.964 | 0.009 |
| | 999 and less | 50 | 3.34 | 1.51 | | | |
| | 1000 to 1999 | 48 | 3.00 | 1.35 | | | |
| | 2000 or more | 15 | 2.40 | 0.91 | | | |
| | **Total** | 166 | 3.27 | 1.48 | | | |
| **Prosocial** | No Income | 53 | 6.89 | 1.72 | F | 3.59 | 0.015 |
| | 999 and less | 50 | 7.84 | 1.86 | | | |
| | 1000 to 1999 | 48 | 7.73 | 1.97 | | | |
| | 2000 or more | 15 | 8.20 | 1.42 | | | |
| | **Total** | 166 | 7.54 | 1.85 | | | |
| **Total difficulties (Emotional+ conduct+ hyperactivity+ peer)** | No Income | 53 | 18.23 | 5.26 | F | 8.749 | 0.000 |
| | 999 and less | 50 | 17.66 | 5.05 | | | |
| | 1000 to 1999 | 48 | 14.48 | 5.22 | | | |
| | 2000 or more | 15 | 12.33 | 4.10 | | | |
| | **Total** | 166 | 16.44 | 5.44 | | | |

As shown in table 4.25, One-way ANOVA-test findings revealed that there were statistically significant differences between total difficulties by their father's work (*P*= 0.000). children whose fathers are not working elicited 18.34 which is the highest mean, followed by children whose fathers are working elicited 15.2 then children with retired fathers elicited 12.75. Scheffe test (Annex 13) showed that there is significant difference between a pair of means: "Yes working" and "No working", (*P*= 0.000) (≤0.05) in favor of those who have no a working father, Scheffe test also showed that there is significant difference between a pair of means: "No working" and "Retired' (*P*= 0.038) in favor of those who have no a working father. The results are logic.

One-way ANOVA-test findings revealed that there were statistically significant differences in the total difficulties among children between their different families' level of income (*P*= 0.000). The family with no income, their children elicited the highest mean (18.23) followed by children with family income 0-999 (17.66) then the children with family income 1000-1999 (14.48) then the children with family income 2000 or more (12.33). Scheffe test (Annex14) shows that there is significant difference between a pair of means: "No income" and "1000 to 1999", *P*= 0.000 (<0.05) in favor of those who have no income, Scheffe test showed that there is significant difference between a pair of means: "up to 999" and "1000 to 1999', (*P*= 0.002) in favor of those who have income with up to 999. There is significant difference between a pair of means "2000 or more" and "No income" in favor of those who have income with 2000 or more and there is significant difference between a pair of means "2000 or more" and "Up to 999", (0.001) in favor of those who have income with up to 999. The results are logic. If the family have more income, they may pay more to meet their children's needs and basic health requirements that are needed to improve the QOL and their children can have enough money to their expenses.

**Differences between total difficulties among children by medical data**

As shown in annex 15, One-way ANOVA-test was conducted to examine if there were significant differences between total difficulties among children with cancer by disease degrees. ANOVA-test findings showed that there were no statistically significant differences between total difficulties among children by disease degrees 0.159 (*P*>0.05).

**Table (4.26) Differences between total difficulties for children in relation to medical data**

| | Medical Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| **Interval since the diagnosis** | | | | | | | |
| **Emotional** | 12 and less | 57 | 5.65 | 2.27 | F | 2.696 | 0.070 |
| | From 13 to 36 | 55 | 4.96 | 2.62 | | | |
| | 37 and more | 54 | 4.57 | 2.53 | | | |
| | **Total** | 166 | 5.07 | 2.50 | | | |
| **Conduct** | 12 and less | 57 | 4.09 | 1.52 | F | 0.407 | 0.666 |
| | From 13 to 36 | 55 | 4.13 | 1.55 | | | |
| | 37 and more | 54 | 3.89 | 1.36 | | | |
| | **Total** | 166 | 4.04 | 1.47 | | | |
| **Hyperactive** | 12 and less | 57 | 5.68 | 1.30 | F | 1.096 | 0.337 |
| | From 13 to 36 | 55 | 5.38 | 1.48 | | | |
| | 37 and more | 54 | 5.81 | 1.88 | | | |
| | **Total** | 166 | 5.63 | 1.57 | | | |
| **Peer** | 12 and less | 57 | 6.28 | 1.44 | F | 2.549 | 0.081 |
| | From 13 to 36 | 55 | 6.27 | 1.21 | | | |
| | 37 and more | 54 | 5.74 | 1.63 | | | |
| | **Total** | 166 | 6.10 | 1.45 | | | |
| **Pre-social** | 12 and less | 57 | 6.97 | 1.94 | F | 4.862 | 0.009 |
| | From 13 to 36 | 55 | 7.66 | 1.88 | | | |
| | 37 and more | 54 | 8.02 | 1.60 | | | |
| | **Total** | 166 | 7.54 | 1.85 | | | |
| **Total difficulties** (Emotional+ conduct+ hyperactivity+ peer) | 12 and less | 57 | 17.81 | 5.20 | F | 3.123 | 0.047 |
| | From 13 to 36 | 55 | 16.13 | 5.66 | | | |
| | 37 and more | 54 | 15.31 | 5.24 | | | |
| | **Total** | 166 | 16.44 | 5.44 | | | |

Using One-way ANOVA-test as shown in table 4.26 to examine whether there were significant differences between total difficulties among children by interval since the diagnosis. One-way ANOVA-test results showed that there were statistically significant differences between total difficulties among children diagnosed with cancer by interval since the diagnosis 0.047 ($P< 0.05$). The children who were diagnosed from 12 & less elicited the higher level of total difficulties and the children who were diagnosed from 37 & more elicited lower level of total difficulties. Scheffe test (Annex 16) shows that there is significant difference between a pair of means: “12 & less” and “37 & more ”, $P= 0.016$ (<0.05) in favor of 12 & less. These results are inconsistent with Salah, Abu Reyala & Al Jerjawy (2018) study results that showed there were no statistically significant differences in the QOL among children by their different diagnosis years of disease ($P= 0.678$) ($P>0.05$).

One-way ANOVA-test was performed to detect whether there was a significant difference between total difficulties scores for children by Suffering from other diseases (Annex 15). Although the children who suffering from other diseases elicited the higher mean (17.50). ANOVA-test results showed that there were no statistically significant differences between total difficulties scores for children by Suffering from other diseases. 0.485($p>0.05$).

**Table (4.27) Differences between total Difficulties for children (Emotional + conduct+ hyperactivity + peer) in relation to cancer type.**

| Cancer type | N | Mean | std | F | Sig |
|---|---|---|---|---|---|
| Leukemia | 110 | 16.79 | 5.49 | | |
| Lymphoma | 24 | 14.81 | 4.59 | | |
| Wilms tumor | 23 | 14.73 | 5.47 | | |
| Brain | 15 | 19.23 | 5.79 | | |
| Neuroblastoma | 15 | 17.00 | 5.77 | | |
| Bone | 10 | 15.00 | 4.10 | | |
| Germ | 5 | 18.00 | 6.93 | | |
| Rhabdosarcoma | 4 | 11.50 | 2.12 | | |
| Other | 3 | 15.33 | 5.13 | | |
| Total | 210 | 16.44 | 5.44 | 1.25 | 0.274 |

As shown in table 4.27, One-way ANOVA-test was conducted to detect whether there were significant differences between total difficulties among children by cancer types. ANOVA-test results showed that there were no statistically significant differences between total difficulties scores for children by cancer types 0.274 ($p>0.05$).

# Chapter Five

## Conclusions and Recommendations

### 5.1 Conclusion

The burden of childhood cancer among children has increased, so it becomes a major problem with unknown causes. A great attention should be directed toward this category. Management of pediatric cancer requires a multidisciplinary team to deal with it. This study to evaluate the provided services to children with cancer to explore the gaps in services. This chapter summarizes the results of study findings in the study and introduce efficient and applicable suggestions and recommendations to improve the current situation.

There are many barriers during the journey of pediatric cancer management, including political situation, division between Gaza Strip and West Bank, referral problems, shortages in the workforce and training, absence or insufficient diagnostic equipment, shortages in essential medicines, unavailability of some treatment modalities and gaps in the information system.

There are shortages in many specialists as oncologists, onco-surgeons, psychologists, nutritionists, pathologists and there is shortage in nurses working in pediatric hematology & oncology department, which adversely affects the management process. There are other challenges include the education programs for all the staff, scholarships and training activities to improve pediatric cancer management

The complicated of political situation and other possible resons affect the availability of diagnostic facilities , where there is total absence in some diagnostic facilities and tests such as (fish studies, flow cytometry (Immune phenotyping), MRD and some of immune stains (Immunohistochemistry), PET scan and obvious shortages in some devices as MRI, CT, where their number is below the international ratios. This is reflected on the quality of the provided services and lead to long waiting tests for diagnostic facilities and referral of children with cancer abroad.

Access to essential medicine is another challenge facing pediatric cancer management in the Gaza Strip due to political situation and absence of clear financing system and that affect negatively on patient and treatment cycle, especially with interruption of some types of chemotherapy and immunotherapy, which adversely affects the application of some chemotherapy protocols as they are. Sometimes the patient being referred outside Gaza to get treatment according to the protocol.

The information system for pediatric cancer including cancer registry, medical files and research activity faces many of gaps. For cancer registry faced gaps due to absence of electronic system and networking between the main health providers in Gaza Strip, absence of enough interest in registration of pediatric cancer cases and deaths number, absence of surveillance system. For medical files also there are no electronic medical files, there is missing information. The research activities about cancer in Gaza is weak and limited to individual work by master's students.

There is application for the international protocols in pediatric chemotherapy and they are unified between Gaza and West Bank and application of protocols depend on what is available in Gaza but there are shortages in application of working policies due to there is no written working policies, shortages in resources and less interest for their application.

The most of children caregivers think the waiting time is reasonable. Approximately more than a third of caregivers and their children suffer from the difficulty in reaching the hospital. External pediatric referrals are always given a priority and there is no long waiting time to refer the child abroad, but in many times, the problem lies in the Israeli occupation polices, that restrict the crossing of patients to the West Bank occupied Palestinian territories.

The majority of children diagnosed with cancer are conducting follow up visits regularly and the doctor respect patient’s appointments. The majority of children diagnosed with cancer underwent to laboratory tests in previous year and received the feedback about the results. This may reflect awareness of caregivers about the importance of conducting follow up regularly and the hospital's interest in alerting patients for continuous follow-up.

Most of caregivers of children diagnosed with cancer satisfied with the provided care, their children health status, waiting time, contact time, building and physical facilities and user provider interaction.

Approximately half of children diagnosed with cancer have psychological issues, as they suffering from substantial risk of clinically significant problems with emotional, conducted, hyperactivity and peer.

## 5.2 Recommendations

- Recruiting experienced-specialists in oncology & oncology surgery, nutritionist and psychological experts in the pediatric oncology department is important step to be taken.
- Invest in training in pediatric oncology is essential.
- Fill gaps in diagnostic services including MRI, CT, PET scan, fish studies, flow cytometry (Immune phenotyping), MRD and some of immune stains (Immunohistochemistry) and providing the unavailable laboratory tests.
- There is a need to update pediatric cancer guidelines and reinforce its implementation.
- To support conducting regular evaluation and auditing the pediatric cancer services.
- Improve documentation practices
- Fosters coordination and communication between facilities providing cancer services.
- Increase contact time during consultation visits and reduce waiting time.
- Enhance the interaction and communication between health provider and caregivers of children with cancer.
- Provide financial assistance to hardship cases to cover costs of services.
- Paying more attention to consider patients' perspectives about the pediatric cancer services and services quality provided and periodically assess their satisfaction about the provided services.
- Promote psychological support to children with cancer and their families.
- Facilite internal and external referrals
- To work collaboratively with local and national and international organizations to advocate the right to health for children with cancer.

## 5.3 Recommendation for further research

- Establishing a special center for health research and conducting additional research in the childhood cancer management and other topics related to cancer.
- Motivating researchers working in oncology departments, local universities and other health programs to conduct ongoing studies related to the management of childhood cancer and the management of other types of cancer to identify barriers and gaps in cancer management to control it.

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# Annexes

## Annex (1): Helsinki Committee research approval

المجلس الفلسطيني للبحث الصحي
Palestinian Health Research Council
تعزيز النظام الصحي الفلسطيني من خلال مأسسة استخدام المعلومات البحثية في صنع القرار
Developing the Palestinian health system through institutionalizing the use of information in decision making

**Helsinki Committee**
**For Ethical Approval**

**Date: 10\08\2020** **Number:** PHRC/HC/749/20

**Name:** Shatha Abdalla El-Habil الاسم:

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 حول:

**Evaluation of Pediatric Cancer Management in the Gaza strip**

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/749/20 in its meeting on 10\08\2020

و قد قررت الموافقة على البحث المذكور عاليه بالرقم والتاريخ المذكوران عاليه

**Signature**

**Member** **Member**

10/8/2020

**Chairman**

10/8/2020

**Genral Conditions:-**

1. Valid for 2 years from the date of approval.
2. It is necessary to notify the committee of any change in the approved study protocol.
3. The committee appreciates receiving a copy of your final research when completed.

**Specific Conditions:-**

12/8/2020

E-Mail:pal.phrc@gmail.com

Gaza - Palestine غزة - فلسطين
شارع النصر - مفترق العيون

**Annex (2): Caregiver's questionnaire**

## Evaluation of Pediatric Cancer Management in the Gaza strip

- I'm Shatha El-Habil and now collecting data for a research study about the evaluation of pediatric cancer management in the Gaza strip. Caregivers of children patients with cancer will be selected in this study and your participation has no direct or indirect negative implications on you or your family.
- Participation in this study requires filling this questionnaire.
- This questionnaire is a part of a study conducted by Shatha El Habil as a requirement for the Master degree in public health at Al-Quds university.
- The aim of this study to assess the status of services are provided for children patients with cancer pediatric cancer in the Gaza strip.
- The questionnaire gives you the opportunity to tell us about status of services are provided to children patients with cancer in the Gaza strip and your perspective about it.
- The findings and conclusions of this study may help in improving the services are provided for children patients with cancer in the Gaza strip.
- Confidentiality will be provided and maintained. You don't need to tell your name
- Respect for truth and respect for human beings will be maintained at all the stages during conducting this study.
- The findings will be used only for the research purposes.
- Even though I welcome and appreciate your participation, participation is optional.
- Please answer all questions as much as possible.
- If you need me to read the question again or you have any ambiguous meaning please don't hesitate to ask for repetition or clarification.
- You have the right to stop or end filling the questionnaire at any point of time and you also have the right to skip any question
- You may feel that some questions are repeated, please try to answer them all

| | | |
|---|---|---|
| Patient serial number …….<br>Day …… Date …… | | |
| Part I | | |
| Section 1: Sociodemographic and economic variables of child patient with cancer | | |
| 1 | What is your relationship with the child patient with cancer? ……... | |
| 2 | Place (by governorate): 1- North Gaza 2- Gaza 3- Middle zone 4- Khanyounis 5-Rafah | |
| 3 | Age of the child patient with cancer | ……. Years |
| 4 | Gender of the child patient with cancer | 1-male 2-female |
| 5 | father working status? 1- Yes working 2- Not working 3- Retired | |
| 6 | Mother working status? 1- Yes working 2- Not working 3- Retired | |
| 7 | What is the monthly income of the child's family (from all sources) ..... ILS | |
| 8 | Does the family receive assistance from any governmental or nongovernmental aid?<br>1 -No 2-yes, from where……. what type of aid.....? | |
| 9 | What is the reason of your today's visit?<br>1 -Scheduled appointed- follow up - 2- Walk-ins- visit 3- To take a chemotherapy dose<br>4-To do laboratory tests - 5- to do medical imaging tests | |
| Section 2: Medical information about the child patient with cancer | | |
| 10 | Type of cancer ……. | |
| 11 | Disease grade at diagnosis 1- low 2- Intermediate 3- high 4- I don't know | |
| 12 | interval since the diagnosis …… | |
| 13 | Does the child patient with cancer have other chronic diseases? 1- Yes 2- No<br>If yes, which diseases do you have …….. | |
| Part II: Input<br>Section 3: | | |
| 1 | What services does the child receive from Rantisii hospital?<br>1. chemotherapy 2. Counseling 3. Follow-up 4. lab tests 5. Medication dispensing 6. Psychological support 7. Medical imaging tests | |
| 2 | In the Rantissi hospital is the child receiving psychosocial services?<br>1-Yes 2. No 3. I don't know | |
| 3 | Your main source of information about children cancer is from<br>1. Physician 2. Family 3. Friend 4. Internet 5. Other, please specify …… | |
| 4 | Do the health services that are needed for the child patient with cancer always available at the Rantissi hospital? 1- Yes 2- No | |
| 5 | If no, list the unavailable services:<br>□ Certain drugs — give example ----------<br>□ Specialized services — give example ---------- (radiation, chemotherapy, surgery)<br>PET scan،bone marrow transplant)<br>□ Laboratory tests — give example ----------<br>Medical imaging tests- give example ……. …….<br>□Other reasons specify ---------- (diagnostic test). | |
| 6 | Do you receive services regarding children cancer from places other than Rantissi hospital?<br>1-yes 2-No If yes, from where do you receive these services? ..... | |

| | |
|---|---|
| 7 | From where does the child patient with cancer get his chemotherapy dose/s? 1-Rantissi hospital 2- 0ther, specify……... |
| 8 | From where does the child patient with cancer get his drug/s? 1-Rantissi hospital 2- 0ther, specify……... |
| 9 | If the child takes his chemotherapy doses from Rantissi hospital, do you find it available every time?<br>1. Yes 2. Not all the time 3. No chemotherapy available |
| 10 | If the child takes his drug/s from pharmacy in Rantissi hospital, do you find it available . every time?<br>1. Yes 2. Not all the time 3. No medication available |
| Part III: Process | |
| Section 4: Waiting time & Pathways | |
| 1 | Was it easy to reach the hospital? 1- Yes 2- No<br>If no, why: - we come on foot and it take a long time<br>we come by public transportation and it is cost money -<br>Others reasons, specify…… |
| 2 | Generally, how many minutes do you wait to receive the children cancer the services from the hospital? ……minutes |
| 3 | From your point of view, do you think the time consumed is?<br>1- Reasonable 2- Lengthy 3- Short |
| 4 | If the child had chemotherapy session in Rantissi hospital, was there a long waiting time before his turn? 1.Yes 2. To some extent 3. No |
| 5 | In case of hospital visit for a follow-up, do you wait for a long time to see the doctor?<br>1. Yes 2. To some extent 3. No |
| 6 | If the child had performed lab tests in the hospital, did you wait for a long time to get the services?<br>1. Yes 2. To some extent 3. No |
| 7 | Staying long time until receiving medications by nurses<br>1. Yes 2. To some extent 3. No |
| 8 | Average waiting time in the external hall (min)?<br>1- <30 2- 30-60 3- >60 |
| 9 | If the pharmacist dispenses drugs for the child patient with cancer, do you wait for a long time to get the services?<br>1-Yes 2. To some extent 3. No . |
| 10 | Is the child experiencing referral to outside?<br>1. Yes 2. No |
| 11 | If yes, Easy to be referred or the child usually has difficulty attaining permit for that??<br>1-Yes 2. To some extent 3. No |
| 12 | Better service at this hospital than abroad<br>1-Yes 2. To some extent 3. No 4. I don't know |
| 13 | Preferring treatment abroad<br>1-Yes 2. To some extent 3. No |
| 14 | Referral is being done due to lack of service<br>1-Yes 2. To some extent 3. No |
| 15 | Was the request to transfer the child abroad via Erez refused before that?<br>1-Yes 2-No<br>How many times was the transfer request rejected …….. |
| 16 | What are the main challenges/barriers you face with regard to services that the child receives from this hospital? 1- Limited availability of therapy ways (few options). 2- Crowdedness of the hospital 3- Lack of specialized and diagnostic services 4- Poor |

| | | | | | | |
|---|---|---|---|---|---|---|
| | staff communication 5- Long waiting time 6- Short contact time with the provider 7- Infrequent appointments 8- Infrequent lab. Analysis | | | | | |
| 17 | In the past year, have you been returned home without receiving the services that the child came to receive? 1- Yes 2- No<br>If yes, indicate why …… | | | | | |
| 18 | If the answer was yes, how many times was the child return home without receiving the needed services? …… | | | | | |
| Section 5: Patient -provider interaction | | | | | | |
| For each of the below statement, please select one of the five options 1=Strongly disagree 2= Disagree 3=Neutral 4=Agree 5=Strongly agree | | | | | | |
| Patient provider interaction | | 1 | 2 | 3 | 4 | 5 |
| 1 | The doctor deals with patients and their caregivers in a friendly way | | | | | |
| 2 | The doctor pay attention to the beliefs and emotions of patients and their caregivers | | | | | |
| 3 | During visiting, you allowed to say everything that you think is important without interruption | | | | | |
| 4 | The doctor listens carefully to everything you say during consultation | | | | | |
| 5 | If you have some questions of a medical nature, you can contact a doctor without problems | | | | | |
| 6 | Do you feel that the doctor understands you? | | | | | |
| 7 | Was it easy to understand what the doctor said? | | | | | |
| 8 | Did the doctor make sure that you understood his explanations and instructions? | | | | | |
| 9 | Did the doctor examine the child patient with cancer thoroughly | | | | | |
| 10 | The doctor responds to all your questions, requests and concerns | | | | | |
| 11 | The doctor always willing to help you | | | | | |
| 12 | In Many times the doctors use a language difficult for you to understand without adequate explanation | | | | | |
| 13 | Did the doctor explain the advantages and disadvantages of the treatment or care strategy? | | | | | |
| 14 | Do you think the doctor told the whole truth? | | | | | |
| 15 | Did the doctor involve you in the decision-making? | | | | | |
| 16 | In your opinion, did the doctor have a reassuring attitude and way of thinking? | | | | | |
| 17 | The doctor respect patient's appointments | | | | | |
| 18 | Does the doctor inform you when to come for the next follow-up? | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| 19 | At emergency, it is easy to contact the doctor | | | | | |
| 20 | Secretaries are courteous, knowledgeable, helpful, and attentive to your needs | | | | | |
| 21 | The nurse deals with patients and their caregivers in a friendly way | | | | | |
| 22 | nurses are courteous, knowledgeable, helpful, and attentive to your needs | | | | | |
| 23 | The nurse never too busy to respond to your request | | | | | |
| 24 | Does the nurse follow the child carefully while you are receiving chemotherapy? | | | | | |
| 25 | Do you feel that the nurse deals with patients fairly | | | | | |
| 26 | Does the nurse provide advice and guidance about the treatment the child is receiving? | | | | | |
| 27 | Does the pharmacist deal with you respectfully? | | | | | |
| 28 | If you want to ask pharmacist anything about the medications, do you find it easy? | | | | | |
| 29 | Does the pharmacist inform you how to give the child his medication every visit? | | | | | |
| 30 | There is good cooperation between the staff | | | | | |

| | |
|---|---|
| Part IV: output/outcome | |
| Section 6: Follow up | |
| 1 | Do you regularly conduct follow up visits? 1- Yes 2- No<br>If no, why?<br>□ I cannot afford transportation cost<br>□ My movement is uneasy<br>□ I do not have time—work issues-leave<br>□ I am not welcomed by staff<br>□ I do not trust my provider<br>□ The providers are not qualified enough to deal with child patient with cancer case<br>□ Others, specify……. |
| 2 | Number of follow-up visits per year? …….. |
| 3 | Do you think that your follow-up visits are adequate?<br>1. Yes 2. To some extent 3. No |
| 4 | Have you been approached by provider because the child did not follow up regularly? 1- Yes 2- No |
| 5 | Has the child patient with cancer done the medical imaging test in previous year? 1- Yes 2- No<br>If yes, when it was? Before .....Months |
| 6 | Have you received feedback about the medical imaging test? 1- Yes 2- No |
| 7 | Has the child patient with cancer done annual laboratory analysis in previous year? 1- Yes 2- No<br>If yes, when it was? Before .....Months |

| | |
|---|---|
| 8 | Have you received feedback about the results of annual laboratory analysis?<br>1-Yes 2- No |
| 9 | If No, why……<br>1. Returned back home without receiving services<br>2. Missing appointments |
| 10 | Is the child doing lab tests at private sites<br>1-Yes 2- No |
| 11 | Physician controls the disease<br>1. Yes 2. To some extent 3. No |
| 12 | Physician alert you about side effects of chemotherapy treatment and how to deal with them<br>1. Yes 2. Sometimes 3. No |
| 13 | Physician is caring to control complications<br>1. Yes 2. To some extent 3. No |
| 14 | Physician prescribes drugs to control complication<br>1. Yes 2. Sometimes 3. No |
| 15 | Physician alert you about side effects of drugs and how to deal with them<br>1. Yes 2. Sometimes 3. No |

Section 7: Satisfaction

1- In general, Have the cancer health services that your child has received meet your expectation?
1- Yes 2-to some extent 3- No If no, why, please specify……..

2- In general, Satisfaction about the child's health status
1-Never 2- No 3- To some extent 4-Satisfy 5-Highly

For each of the below statement, please select one of the five options 1=Strongly disagree 2= Disagree 3=Natural 4=Agree 5=Strongly agree

| | | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|---|
| 1 | The service providers are well dressed and appear neat | | | | | |
| 2 | Hospital environment is comfortable (cleanliness, space, quiet and so on) | | | | | |
| 3 | The nature of the place is suitable for children | | | | | |
| 4 | There are enough toilets in hospital | | | | | |
| 5 | hospital toilets are clean | | | | | |
| 6 | The hospital is equipped with modern and up-to date equipment | | | | | |
| 7 | The hospital operating hours are convenient to you | | | | | |
| 8 | Booking an appointment is easy | | | | | |
| 9 | Waiting time is long | | | | | |
| 10 | You are satisfied with Welcoming and greeting of service providers | | | | | |
| 11 | The staff collaborate with patients | | | | | |
| 12 | The time that the health providers spent with patient is enough | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| 13 | The child usually has difficulty attaining referrals for medical imaging tests? | | | | | |
| 14 | You have easy access to the specialists your child is needing | | | | | |
| 15 | Some of the doctors you have seen lack experience with child medical problems | | | | | |
| 16 | The services providers respect of patient privacy | | | | | |
| 17 | The medical care that the child patient with cancer has been receiving is just about perfect | | | | | |
| 18 | The doctors are good about explaining the reason for medical test | | | | | |
| 19 | the way services providers tell you about improving the child health | | | | | |
| 20 | When the child undergoes a medical examination, you are sure that everything is checked and examined the doctors are doing their best to prevent you from worrying unnecessarily | | | | | |
| 21 | Having enough information about the disease | | | | | |
| 22 | You satisfied with the medical care that the child is receiving | | | | | |
| 23 | Visiting hours are very comfortable | | | | | |
| 24 | To what extent do you think the human resources are adequate in number? | | | | | |
| 25 | To what extent do you think the available human resources have the needed qualifications? | | | | | |

Section 8: Using (SDQ questionnaire), Please give your answers on the basis of your child's behavior over the last six months (Not true, somewhat true, certainly true)

| | | Not true | Some what true | Certainly true |
|---|---|---|---|---|
| 1 | Considerate of other people's feelings | | | |
| 2 | Restless, overactive, cannot stay still for long | | | |
| 3 | Often complains of headaches, stomach-aches or sickness | | | |
| 4 | Shares readily with other children, for example toys, treats, pencils | | | |
| 5 | Often loses temper | | | |
| 6 | Rather solitary, prefers to play alone | | | |
| 7 | Generally, well behaved, usually does what adults request | | | |
| 8 | Many worries or often seems worried | | | |
| 9 | Helpful if someone is hurt, upset or feeling ill | | | |
| 10 | Constantly fidgeting or squirming | | | |
| 11 | Has at least one good friend | | | |
| 12 | Often fights with other children or bullies them | | | |
| 13 | Often unhappy, depressed or tearful | | | |
| 14 | Generally liked by other children | | | |
| 15 | Easily distracted, concentration wanders | | | |
| 16 | Nervous or clingy in new situations, easily loses confidence | | | |

| | | | | |
|---|---|---|---|---|
| 17 | Kind to younger children | | | |
| 18 | Often lies or cheats | | | |
| 19 | Picked on or bullied by other children | | | |
| 20 | Often volunteers to help others (parents, teachers, other children) | | | |
| 21 | Thinks things out before acting | | | |
| 22 | Steals from home, school or elsewhere | | | |
| 23 | Gets along better with adults than with other children | | | |
| 24 | Many fears, easily scared | | | |
| 25 | Good attention span, sees chores or homework through to the end | | | |

## Annex (3): Completeness of medical files for children with cancer

| | | | | | |
|---|---|---|---|---|---|
| | Serial Number: | | | | |
| | Member name: | DOB: | Member ID: | | |
| | Provider name: | | | | |
| | Reviewer: | Date: | | | |
| | | | yes | No | NA |
| I | Patient identification | | | | |
| 1 | Each page within the Medical Record contains the patient's name | | | | |
| 2 | Each page within the Medical Record contains the patient's ID number | | | | |
| II | Patient Biographical data | | | | |
| 1 | Each page within the Medical Record contains the patient's age | | | | |
| 2 | Each page within the Medical Record contains the patient's DOB | | | | |
| 3 | Each page within the Medical Record contains the patient's gender | | | | |
| 4 | Each page within the Medical Record contains the patient's address | | | | |
| 5 | Each page within the Medical Record contains the patient's home telephone number | | | | |
| III | Medical record characteristic | | | | |
| 1 | The main purpose of the patient's visit is clearly documented | | | | |
| 2 | Appropriated diagnoses are recorded | | | | |
| 3 | Is ICD10 used? | | | | |
| 4 | Diagnostic tests laboratory, radiology and pathology are listed for each visit | | | | |
| 5 | All entries in the Medical Record contain the author's identification Author identification may be a handwritten signature, initials, an initials-stamped signature or a unique electronic identifier | | | | |
| 6 | All entries in the Medical Record are dated | | | | |
| 7 | Is the record an Electronic Medical Record (EMR) | | | | |
| 8 | If a consultation or diagnostic study is requested, there is a note or report from the consultant in the record | | | | |
| 9 | Relevant hospital discharge summaries are included with the medical record | | | | |
| IV | Medication Record | | | | |
| 1 | Medications are documented for each visit | | | | |
| 2 | A medication record/list includes dosages and dates for initial and refill prescription | | | | |
| 3 | Discussion of medication side effects and symptoms with caregiver and documented | | | | |
| 4 | Allergies and adverse reactions are prominently noted in the record. Prominently noted in 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 | | | | |
| V | The history and physical exam | | | | |
| 1 | Family history- including medical history of parents and/or sibling (s) | | | | |
| 2 | Medical- surgical history including surgical, injuries, operations and acute or chronic diseases/illnesses | | | | |
| 3 | A comprehensive review of systems with an assessment of presenting complaints (as applicable) | | | | |
| VI | Chemotherapy record | | | | |

| | | | | |
|---|---|---|---|---|
| 1 | Chemotherapy treatment plan request model has a clear diagnosis | | | |
| 2 | Chemotherapy treatment plan model has a clear weight and height for the patient | | | |
| 3 | Chemotherapy treatment plan model has a clear body surface area | | | |
| 4 | Chemotherapy plan regimen table in the request is filled | | | |
| 5 | Chemotherapy regimen plan has a clear author's identification | | | |
| VII | Cancer related characteristics | | | |
| 1 | Is the histopathology report available? | | | |
| 2 | Does the behavior (aggressive-metastasis) mentioned? | | | |
| 3 | Does the file contain a clear grading system for the cancer? | | | |
| 4 | Does the staging of the cancer clearly mentioned? | | | |

**Annex (4): Key informants interview questions:**

السيداة:

أنا الطالبة شذا عبدالله الهبيل، ملتحقة ببرنامج ماجستير الصحة العامة– تخصص إدارة صحية– جامعة القدس

لقد تم اختيارك للمشاركة في هذه الدراسة التي تهدف إلى تقييم الخدمات المقدمة لأطفال مرضى السرطان في غزة وتم اختيارك بشكل استراتيجي لأن لديك معرفة ودراية بالخدمات المقدمة لأطفال السرطان في غزة. .و أنا ممتنة لوقتك واستعدادك للمشاركة

قد تساعد نتائج واستنتاجات هذه الدراسة في تحسين الخدمات المقدمة للأطفال المصابين بالسرطان في قطاع غزة

هذه الدراسة متطلب للحصول على درجة الماجستير–جامعة القدس أبوديس

اشتراكك في هذه الرسالة تطوعية يحق لك القبول أو الرفض

لا يوجد إجابات صحيحة أو خاطئة

السرية مكفولة

ستستغرق مدة اللقاء حوالي 60 دقيقة

شكرا لتعاونكم

| | |
|---|---|
| Name of interviewer | |
| Position of interviewer | |
| Name of interviewee | |
| Place of interview | |
| Date of interview | |

1-Being one of the key persons in health, where are we from pediatric cancer as a health problem in the Gaza strip?

**Probing questions**

Size of problem?

Public suffering?

2- What do you think about the services available for children with cancer?

Probing questions

- What do you think about the quality of services received by the children patient of cancer?
- What are the missing services, what needs to be done?
- Treatment (Radiotherapy, surgery, chemotherapy)
- Time taken for diagnosis
- Psychological support
- Information health education

3- Are there strategies and protocols for the management and control of cancer?

**Probing questions**

- accessible?
- applicable?
- Renewable?
- Effective

4-Can you talk about internal and external referral system process?

**Probing questions**

- Are you are satisfied with internal referral system?
- Are you are satisfied with external referral system?

5-What do you think about children cancer available information system and research activities in the Gaza strip?

6-Could you tell me about current infrastructure used to diagnose and treatment of children cancer and your opinion about it?

**Probing questions**

- Human resources (number, distribution, qualification, training, scholarship sex and age)

-Diagnostic facilities, diagnostic facilities experts, diagnostic facilities maintenance-

-Building quality and physical space facilities-

7- What are the major obstacles health care system face in controlling pediatric cancer?

**Probing questions**

- Strategies and protocols

- Limited availability of services
- Quality of services
- Accessibility
- Referral system
- Follow up

8- Do you have other questions?

Thank a lot for your time and efforts

**Annex (5): Staff Questions**

1- Do you have written protocols and technical instructions related to pediatric cancer

**Probing questions**

- Can you access to such protocols, if available?
- Have you been trained on those protocols?
- Are these protocols up to date
- Do you think the colleagues fully applying the written protocols?
- If you have the option, what could you add to the current protocol?

2- How do you evaluate the quality of services provided to children patient with cancer?

**Probing questions**

- Are you satisfied with the quality of provided services?
- if you are not satisfied? what could be done to improve the quality of services?

3- From your perspectives, how do you evaluate the contact time with clients?

**Probing questions**

- If short, what are the barriers that prevent achieving the required contact time?
- What could be done to achieve the required contact time?

4- To what extent do you think that you have the appropriate knowledge and skills needed for pediatric cancer management?

**Probing questions**

To large extend, how?

Not at all, why?

5- To what extent do you think that you have the appropriate experiences needed for pediatric cancer management?

**Probing questions**

To large extend, how?

Not at all, why?

6- Do you have in-service training program related to pediatric cancer management?

**Probing questions**

- If yes how often do they provide trainings?
- What topics were covered
- What trainings you wish to have?

7- From your view, what are the main obstacles that prevent children patient with cancer from utilizing the services?

**Probing questions**

Limited availability of services

Limited of specialized services

Limited of diagnostic facilities

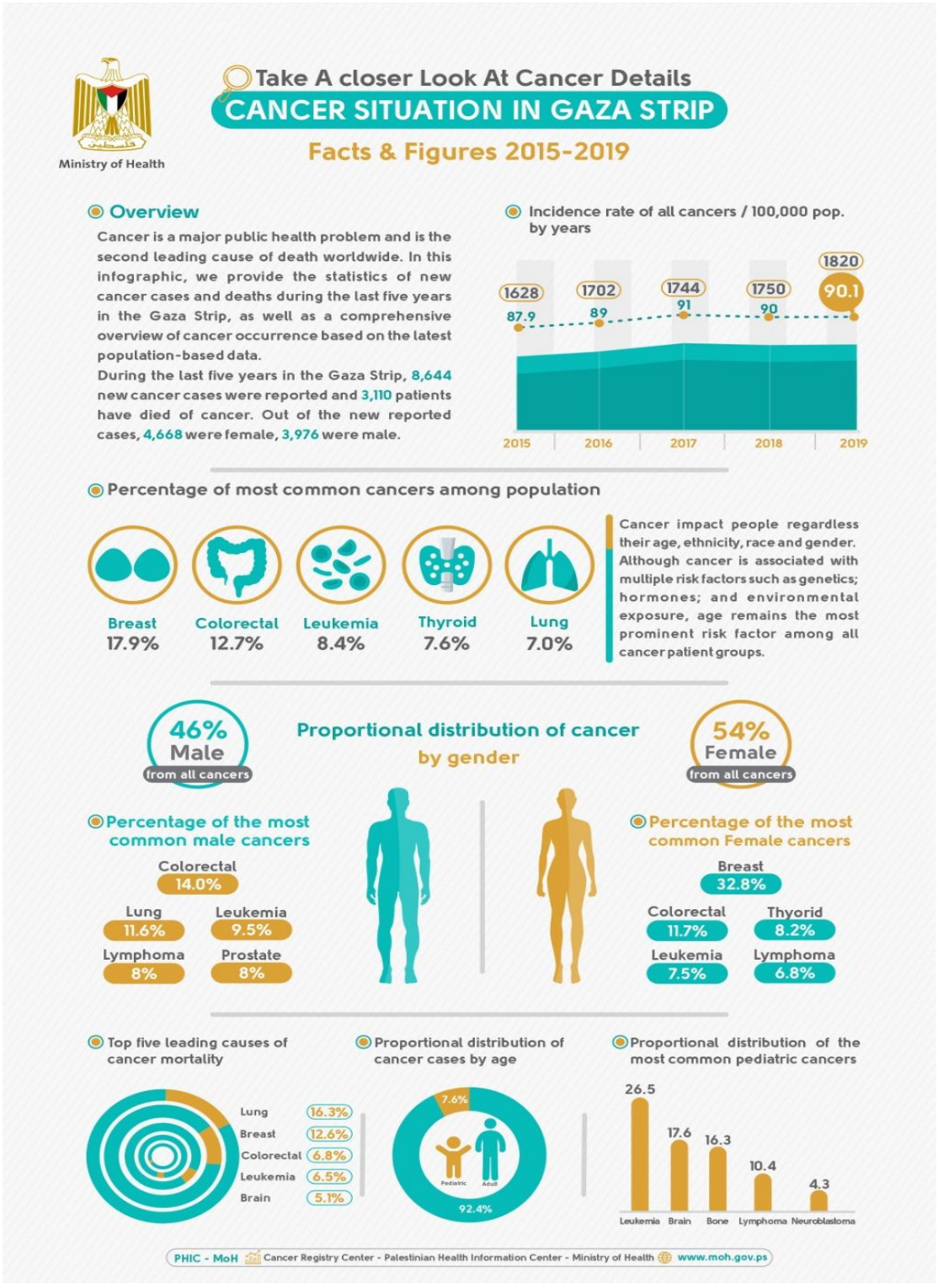
Waiting time

Work schedule

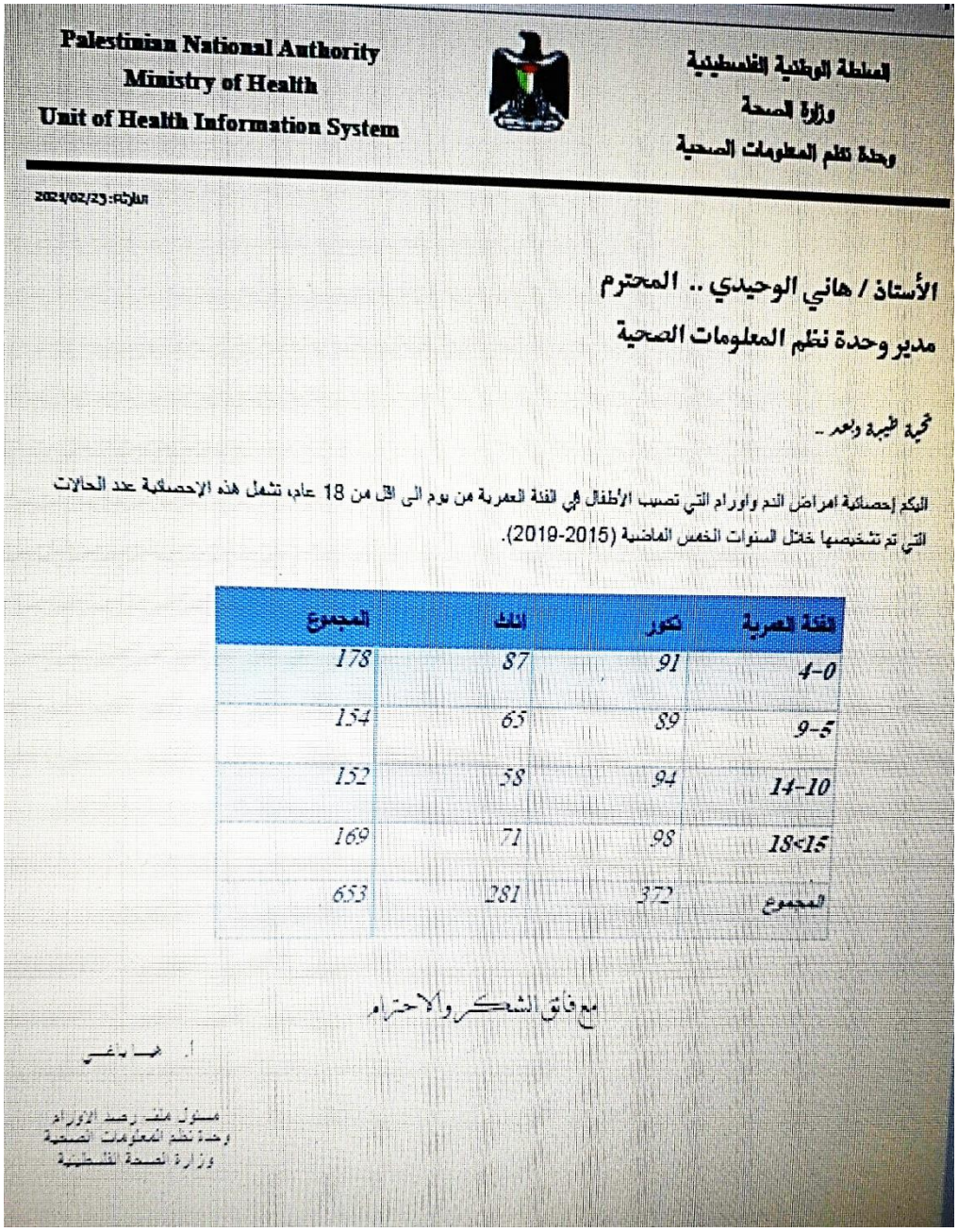
8- Do you have other questions?

Thank a lot for your time and efforts

## Annex (6): MOH infographic (1)



**Annex (7): MOH report -Unit of health information system**



Palestinian National Authority
Ministry of Health
Unit of Health Information System

السلطة الوطنية الفلسطينية
وزارة الصحة
وحدة نظم المعلومات الصحية

التاريخ: 2021/02/23

الأستاذ / هاني الوحيدي .. المحترم
مدير وحدة نظم المعلومات الصحية

تحية طيبة وبعد ..

البكم إحصائية امراض الدم واورام التي تصيب الأطفال في الفئة العمرية من يوم الى اقل من 18 عام، تشمل هذه الإحصائية عدد الحالات التي تم تشخيصها خلال السنوات الخمس الماضية (2015-2019).

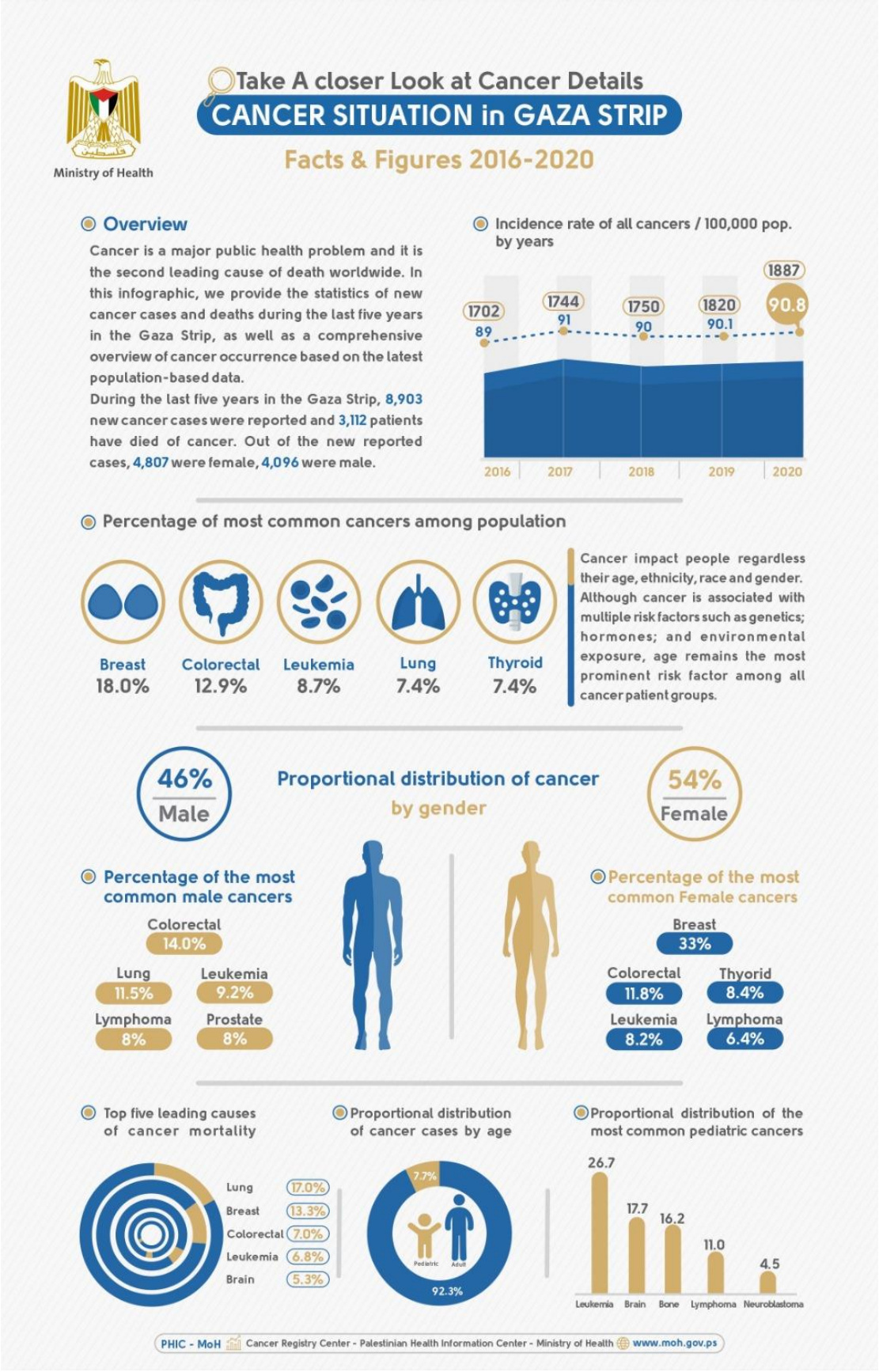
| الفئة العمرية | ذكور | اناث | المجموع |
|---|---|---|---|
| 4-0 | 91 | 87 | 178 |
| 9-5 | 89 | 65 | 154 |
| 14-10 | 94 | 58 | 152 |
| 18<15 | 98 | 71 | 169 |
| المجموع | 372 | 281 | 653 |

مع فائق الشكر والاحترام

أ. [illegible]

مسؤول مكتب رصد الاورام
وحدة نظم المعلومات الصحية
وزارة الصحة الفلسطينية

## Annex (8): MOH infographic (2)



## Annex (9): Scheffe test for differences between user-provider interaction in relation to disease degree

| **Dependent Variable: User-provider interaction** | | | | | | |
|---|---|---|---|---|---|---|
| LSD | | | | | | |
| **(I) diseasedegree** | **(J) diseasedegree** | **Mean Difference (I-J)** | **Std. Error** | **Sig.** | **95% Confidence Interval** | |
| | | | | | **Lower Bound** | **Upper Bound** |
| Low | Intermediate | -.21082- | .11870 | .077 | -.4449- | .0232 |
| | High | .01353 | .10629 | .899 | -.1960- | .2231 |
| | I dont know | -.28513-* | .10583 | .008 | -.4938- | -.0765- |
| Intermediate | Low | .21082 | .11870 | .077 | -.0232- | .4449 |
| | High | .22435* | .09818 | .023 | .0308 | .4179 |
| | I dont know | -.07431- | .09769 | .448 | -.2669- | .1183 |
| High | Low | -.01353- | .10629 | .899 | -.2231- | .1960 |
| | Intermediate | -.22435-* | .09818 | .023 | -.4179- | -.0308- |
| | I dont know | -.29866-* | .08216 | .000 | -.4607- | -.1367- |
| I dont know | Low | .28513* | .10583 | .008 | .0765 | .4938 |
| | Intermediate | .07431 | .09769 | .448 | -.1183- | .2669 |
| | High | .29866* | .08216 | .000 | .1367 | .4607 |
| *. The mean difference is significant at the 0.05 level. | | | | | | |

**Annex (10): . Scheffe test for differences between satisfaction in relation to disease degree**

| Dependent variable: Satisfaction | | | | | | |
|---|---|---|---|---|---|---|
| LSD | | | | | | |
| (I) diseasedegree | (J) diseasedegree | Mean Difference (I-J) | Std. Error | Sig. | 95% Confidence Interval | |
| | | | | | Lower Bound | Upper Bound |
| Low | Intermediate | -.09521- | .06678 | .155 | -.2269- | .0365 |
| | High | -.00288- | .05979 | .962 | -.1208- | .1150 |
| | I dont know | -.11901-* | .05967 | .047 | -.2367- | -.0014- |
| Intermediate | Low | .09521 | .06678 | .155 | -.0365- | .2269 |
| | High | .09234 | .05523 | .096 | -.0166- | .2012 |
| | I dont know | -.02380- | .05509 | .666 | -.1324- | .0848 |
| High | Low | .00288 | .05979 | .962 | -.1150- | .1208 |
| | Intermediate | -.09234- | .05523 | .096 | -.2012- | .0166 |
| | I dont know | -.11613-* | .04638 | .013 | -.2076- | -.0247- |
| I dont know | Low | .11901* | .05967 | .047 | .0014 | .2367 |
| | Intermediate | .02380 | .05509 | .666 | -.0848- | .1324 |
| | High | .11613* | .04638 | .013 | .0247 | .2076 |

## Annex (11): Scheffe test for differences between satisfaction in relation to cancer type

| Multiple Comparisons | | | | | | |
|---|---|---|---|---|---|---|
| Dependent Variable: satisfaction | | | | | | |
| LSD | | | | | | |
| (I) cancertypenum | (J) cancertypenum | Mean Difference (I-J) | Std. Error | Sig. | 95% Confidence Interval | |
| | | | | | Lower Bound | Upper Bound |
| leukemia | lymphoma | -.17358-* | .06143 | .005 | -.2947- | -.0524- |
| | wilms tumor | -.07595- | .06252 | .226 | -.1992- | .0473 |
| | brain | .09629 | .07505 | .201 | -.0517- | .2443 |
| | neuroblastoma | -.12558- | .07505 | .096 | -.2736- | .0224 |
| | bone | -.14051- | .09006 | .120 | -.3181- | .0371 |
| | germ | -.03171- | .12469 | .800 | -.2776- | .2142 |
| | rhabdo | -.01891- | .13880 | .892 | -.2926- | .2548 |
| | other | -.22158- | .15956 | .166 | -.5362- | .0931 |
| Lymphoma | leukemia | .17358* | .06143 | .005 | .0524 | .2947 |
| | wilms tumor | .09762 | .07957 | .221 | -.0593- | .2545 |
| | brain | .26987* | .08975 | .003 | .0929 | .4468 |
| | neuroblastoma | .04800 | .08975 | .593 | -.1290- | .2250 |
| | bone | .03307 | .10263 | .748 | -.1693- | .2354 |
| | germ | .14187 | .13405 | .291 | -.1225- | .4062 |
| | rhabdo | .15467 | .14726 | .295 | -.1357- | .4451 |
| | other | -.04800- | .16698 | .774 | -.3773- | .2813 |
| wilms tumor | leukemia | .07595 | .06252 | .226 | -.0473- | .1992 |
| | lymphoma | -.09762- | .07957 | .221 | -.2545- | .0593 |
| | brain | .17224 | .09050 | .058 | -.0062- | .3507 |
| | neuroblastoma | -.04962- | .09050 | .584 | -.2281- | .1288 |
| | bone | -.06456- | .10329 | .533 | -.2682- | .1391 |
| | germ | .04424 | .13455 | .743 | -.2211- | .3096 |
| | rhabdo | .05704 | .14772 | .700 | -.2342- | .3483 |
| | other | -.14562- | .16738 | .385 | -.4757- | .1844 |
| Brain | leukemia | -.09629- | .07505 | .201 | -.2443- | .0517 |
| | lymphoma | -.26987-* | .08975 | .003 | -.4468- | -.0929- |
| | wilms tumor | -.17224- | .09050 | .058 | -.3507- | .0062 |
| | neuroblastoma | -.22187-* | .09957 | .027 | -.4182- | -.0255- |
| | bone | -.23680-* | .11132 | .035 | -.4563- | -.0173- |
| | germ | -.12800- | .14081 | .364 | -.4057- | .1497 |
| | rhabdo | -.11520- | .15345 | .454 | -.4178- | .1874 |
| | other | -.31787- | .17246 | .067 | -.6579- | .0222 |
| Neuroblastoma | leukemia | .12558 | .07505 | .096 | -.0224- | .2736 |
| | lymphoma | -.04800- | .08975 | .593 | -.2250- | .1290 |
| | wilms tumor | .04962 | .09050 | .584 | -.1288- | .2281 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | brain | .22187* | .09957 | .027 | .0255 | .4182 |
| | bone | -.01493- | .11132 | .893 | -.2344- | .2046 |
| | germ | .09387 | .14081 | .506 | -.1838- | .3715 |
| | rhabdo | .10667 | .15345 | .488 | -.1959- | .4092 |
| | other | -.09600- | .17246 | .578 | -.4361- | .2441 |
| Bone | leukemia | .14051 | .09006 | .120 | -.0371- | .3181 |
| | lymphoma | -.03307- | .10263 | .748 | -.2354- | .1693 |
| | wilms tumor | .06456 | .10329 | .533 | -.1391- | .2682 |
| | brain | .23680* | .11132 | .035 | .0173 | .4563 |
| | neuroblastoma | .01493 | .11132 | .893 | -.2046- | .2344 |
| | germ | .10880 | .14935 | .467 | -.1857- | .4033 |
| | rhabdo | .12160 | .16132 | .452 | -.1965- | .4397 |
| | other | -.08107- | .17950 | .652 | -.4350- | .2729 |
| Germ | leukemia | .03171 | .12469 | .800 | -.2142- | .2776 |
| | lymphoma | -.14187- | .13405 | .291 | -.4062- | .1225 |
| | wilms tumor | -.04424- | .13455 | .743 | -.3096- | .2211 |
| | brain | .12800 | .14081 | .364 | -.1497- | .4057 |
| | neuroblastoma | -.09387- | .14081 | .506 | -.3715- | .1838 |
| | bone | -.10880- | .14935 | .467 | -.4033- | .1857 |
| | rhabdo | .01280 | .18292 | .944 | -.3479- | .3735 |
| | other | -.18987- | .19914 | .342 | -.5825- | .2028 |
| rhabdo | leukemia | .01891 | .13880 | .892 | -.2548- | .2926 |
| | lymphoma | -.15467- | .14726 | .295 | -.4451- | .1357 |
| | wilms tumor | -.05704- | .14772 | .700 | -.3483- | .2342 |
| | brain | .11520 | .15345 | .454 | -.1874- | .4178 |
| | neuroblastoma | -.10667- | .15345 | .488 | -.4092- | .1959 |
| | bone | -.12160- | .16132 | .452 | -.4397- | .1965 |
| | germ | -.01280- | .18292 | .944 | -.3735- | .3479 |
| | other | -.20267- | .20826 | .332 | -.6133- | .2080 |
| other | leukemia | .22158 | .15956 | .166 | -.0931- | .5362 |
| | lymphoma | .04800 | .16698 | .774 | -.2813- | .3773 |
| | wilms tumor | .14562 | .16738 | .385 | -.1844- | .4757 |
| | brain | .31787 | .17246 | .067 | -.0222- | .6579 |
| | neuroblastoma | .09600 | .17246 | .578 | -.2441- | .4361 |
| | bone | .08107 | .17950 | .652 | -.2729- | .4350 |
| | germ | .18987 | .19914 | .342 | -.2028- | .5825 |
| | rhabdo | .20267 | .20826 | .332 | -.2080- | .6133 |

**Annex (12):Differences in total difficulties in relation to demographic data**

| | Demographic Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| **Gender** | | | | | | | |
| **Emotional** | Male | 85 | 4.82 | 2.62 | t | -1.316 | 0.190 |
| | Female | 81 | 5.33 | 2.36 | | | |
| **Conducted** | Male | 85 | 3.41 | 1.48 | t | 0.745 | 0.458 |
| | Female | 81 | 3.23 | 1.58 | | | |
| **Hyperactivity** | Male | 85 | 4.89 | 1.76 | t | 0.961 | 0.338 |
| | Female | 81 | 4.64 | 1.62 | | | |
| **Peer** | Male | 85 | 3.28 | 1.55 | t | 0.100 | 0.920 |
| | Female | 81 | 3.26 | 1.42 | | | |
| **Prosocial** | Male | 85 | 7.61 | 1.79 | t | 0.537 | 0.592 |
| | Female | 81 | 7.46 | 1.92 | | | |
| **Total difficulties (Emotional+ conduct+ hyperactivity+ peer)** | Male | 85 | 16.41 | 5.61 | t | -0.068 | 0.946 |
| | Female | 81 | 16.47 | 5.29 | | | |
| **Age** | | | | | | | |
| **Emotional** | Less than 5 | 22 | 5.41 | 2.34 | F | 0.708 | 0.494 |
| | From 5 to 9 | 93 | 5.17 | 2.56 | | | |
| | More than 9 | 51 | 4.75 | 2.47 | | | |
| | **Total** | 166 | 5.07 | 2.50 | | | |
| **Conducted** | Less than 5 | 22 | 3.45 | 1.41 | F | 0.290 | 0.749 |
| | From 5 to 9 | 93 | 3.37 | 1.52 | | | |
| | More than 9 | 51 | 3.20 | 1.63 | | | |
| | **Total** | 166 | 3.33 | 1.53 | | | |
| **Hyperactivity** | Less than 5 | 22 | 5.14 | 1.55 | F | 0.591 | 0.555 |
| | From 5 to 9 | 93 | 4.71 | 1.71 | | | |
| | More than 9 | 51 | 4.73 | 1.72 | | | |
| | **Total** | 166 | 4.77 | 1.69 | | | |
| **Peer** | Less than 5 | 22 | 3.91 | 1.48 | F | 2.558 | 0.081 |
| | From 5 to 9 | 93 | 3.23 | 1.47 | | | |
| | More than 9 | 51 | 3.08 | 1.47 | | | |
| | **Total** | 166 | 3.27 | 1.48 | | | |
| **Per social** | Less than 5 | 22 | 7.23 | 1.41 | F | 1.679 | 0.190 |
| | From 5 to 9 | 93 | 7.40 | 2.06 | | | |
| | More than 9 | 51 | 7.92 | 1.56 | | | |
| | **Total** | 166 | 7.54 | 1.85 | | | |
| **Total difficulties (Emotional+ conduct+ hyperactivity+ peer)** | Less than 5 | 22 | 17.91 | 5.18 | F | 1.223 | 0.297 |
| | From 5 to 9 | 93 | 16.47 | 5.40 | | | |
| | More than 9 | 51 | 15.75 | 5.60 | | | |
| | **Total** | 166 | 16.44 | 5.44 | | | |
| **Governorates** | | | | | | | |
| **Emotional** | North | 35 | 5.54 | 2.25 | F | 1.407 | 0.234 |
| | Gaza | 76 | 4.68 | 2.55 | | | |
| | Middle zone | 15 | 6.00 | 2.04 | | | |
| | Khan Younis | 23 | 4.83 | 2.55 | | | |
| | Rafah | 17 | 5.35 | 2.91 | | | |
| | **Total** | 166 | 5.07 | 2.50 | | | |
| **Conducted** | North | 35 | 3.43 | 1.44 | | 0.886 | 0.474 |

| | Demographic Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| | Gaza | 76 | 3.09 | 1.54 | F | | |
| | Middle zone | 15 | 3.53 | 1.46 | | | |
| | Khan Younis | 23 | 3.65 | 1.53 | | | |
| | Rafah | 17 | 3.53 | 1.74 | | | |
| | **Total** | 166 | 3.33 | 1.53 | | | |
| **Hyperactivity** | North | 35 | 4.89 | 1.37 | | 1.648 | 0.165 |
| | Gaza | 76 | 4.53 | 1.83 | F | | |
| | Middle zone | 15 | 5.27 | 1.67 | | | |
| | Khan Younis | 23 | 5.35 | 1.61 | | | |
| | Rafah | 17 | 4.41 | 1.62 | | | |
| | **Total** | 166 | 4.77 | 1.69 | | | |
| **Peer** | North | 35 | 3.66 | 1.26 | | 3.15 | 0.016 |
| | Gaza | 76 | 2.96 | 1.41 | F | | |
| | Middle zone | 15 | 3.73 | 1.39 | | | |
| | Khan Younis | 23 | 2.91 | 1.38 | | | |
| | Rafah | 17 | 3.94 | 2.02 | | | |
| | **Total** | 166 | 3.27 | 1.48 | | | |
| **prosocial** | North | 35 | 7.49 | 1.95 | | 0.115 | 0.977 |
| | Gaza | 76 | 7.54 | 1.96 | F | | |
| | Middle zone | 15 | 7.33 | 1.84 | | | |
| | Khan Younis | 23 | 7.57 | 1.59 | | | |
| | Rafah | 17 | 7.77 | 1.72 | | | |
| | **Total** | 166 | 7.54 | 1.85 | | | |
| **Total difficulties (Emotional+ conduct+ hyperactivity+ peer)** | North | 35 | 17.51 | 4.63 | | 1.936 | 0.107 |
| | Gaza | 76 | 15.26 | 5.50 | F | | |
| | Middle zone | 15 | 18.53 | 5.17 | | | |
| | Khan Younis | 23 | 16.74 | 4.96 | | | |
| | Rafah | 17 | 17.24 | 6.86 | | | |
| | **Total** | 166 | 16.44 | 5.44 | | | |
| **Mother Work** | | | | | | | |
| **Emotional** | Yes | 11 | 4.64 | 2.38 | t | -0.597 | 0.551 |
| | No | 155 | 5.10 | 2.51 | | | |
| **Conducted** | Yes | 11 | 1.82 | 0.87 | t | -1.089 | 0.278 |
| | No | 155 | 2.11 | 0.86 | | | |
| **Hyperactivity** | Yes | 11 | 4.36 | 2.01 | t | -0.827 | 0.410 |
| | No | 155 | 4.80 | 1.67 | | | |
| **Peer** | Yes | 11 | 2.55 | 1.04 | t | -1.689 | 0.093 |
| | No | 155 | 3.32 | 1.50 | | | |
| **Prosocial** | Yes | 11 | 8.09 | 1.70 | t | 1.027 | 0.306 |
| | No | 155 | 7.50 | 1.86 | | | |
| **Total difficulties (Emotional+ conduct+ hyperactivity+ peer)** | Yes | 11 | 14.27 | 4.98 | t | -1.371 | 0.172 |
| | No | 155 | 16.59 | 5.45 | | | |
| **Receiving Assistant** | | | | | | | |
| **Emotional** | Yes | 52 | 5.62 | 2.57 | t | 1.905 | 0.058 |
| | No | 114 | 4.82 | 2.44 | | | |
| **Conducted** | Yes | 52 | 2.29 | 0.89 | t | 2.026 | 0.044 |
| | No | 114 | 2.00 | 0.83 | | | |
| **Hyperactivity** | Yes | 52 | 5.19 | 1.96 | t | 2.194 | 0.030 |

| | Demographic Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| | No | 114 | 4.58 | 1.52 | | | |
| **Peer** | Yes | 52 | 3.52 | 1.78 | t | 1.461 | 0.146 |
| | No | 114 | 3.16 | 1.32 | | | |
| **Prosocial** | Yes | 52 | 6.98 | 2.08 | t | -2.654 | 0.009 |
| | No | 114 | 7.79 | 1.69 | | | |
| **Total difficulties (Emotional+ conduct+ hyperactivity+ peer)** | Yes | 52 | 18.06 | 5.84 | t | 2.634 | 0.009 |
| | No | 114 | 15.70 | 5.11 | | | |

## Annex (13): . Scheffe test for differences between total difficulties in relation to father's work

| Dependent Variable: Total difficulties | | | | | | |
|---|---|---|---|---|---|---|
| LSD | | | | | | |
| (I) fatherworking | (J) fatherworking | Mean Difference (I-J) | Std. Error | Sig. | 95% Confidence Interval | |
| | | | | | Lower Bound | Upper Bound |
| yes working | No working | -3.21715-* | .82422 | .000 | -4.8447- | -1.5896- |
| | Retired | 2.37088 | 2.65918 | .374 | -2.8800- | 7.6218 |
| No working | yes working | 3.21715* | .82422 | .000 | 1.5896 | 4.8447 |
| | Retired | 5.58803* | 2.67490 | .038 | .3061 | 10.8699 |
| Retired | yes working | -2.37088- | 2.65918 | .374 | -7.6218- | 2.8800 |
| | No working | -5.58803-* | 2.67490 | .038 | -10.8699- | -.3061- |
| *. The mean difference is significant at the 0.05 level. | | | | | | |

## Annex (14): . Scheffe test for differences between total difficulties in relation to income

Dependent Variable: Total difficulties

LSD

| (I) Salary_cat | (J) Salary_cat | Mean Difference (I-J) | Std. Error | Sig. | 95% Confidence Interval | |
|---|---|---|---|---|---|---|
| | | | | | Lower Bound | Upper Bound |
| No Income | 999 and less | .56642 | 1.00429 | .574 | -1.4168- | 2.5496 |
| | 1000 to 1999 | 3.74725* | 1.01500 | .000 | 1.7429 | 5.7516 |
| | 2000 or more | 5.89308* | 1.48982 | .000 | 2.9511 | 8.8351 |
| 999 and less | No Income | -.56642- | 1.00429 | .574 | -2.5496- | 1.4168 |
| | 1000 to 1999 | 3.18083* | 1.02937 | .002 | 1.1481 | 5.2135 |
| | 2000 or more | 5.32667* | 1.49965 | .001 | 2.3653 | 8.2881 |
| 1000 to 1999 | No Income | -3.74725-* | 1.01500 | .000 | -5.7516- | -1.7429- |
| | 999 and less | -3.18083-* | 1.02937 | .002 | -5.2135- | -1.1481- |
| | 2000 or more | 2.14583 | 1.50684 | .156 | -.8298- | 5.1214 |
| 2000 or more | No Income | -5.89308-* | 1.48982 | .000 | -8.8351- | -2.9511- |
| | 999 and less | -5.32667-* | 1.49965 | .001 | -8.2881- | -2.3653- |
| | 1000 to 1999 | -2.14583- | 1.50684 | .156 | -5.1214- | .8298 |

**Annex (15) Differences between total difficulties for children in relation to medical data**

| | Medical Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| **Diseases Grade** | | | | | | | |
| **Emotional** | Low | 23 | 5.43 | 1.78 | F | 1.941 | 0.125 |
| | Intermediate | 30 | 5.67 | 2.62 | | | |
| | High | 53 | 5.23 | 2.54 | | | |
| | I Don't Know | 59 | 4.47 | 2.60 | | | |
| | **Total** | 165 | 5.07 | 2.51 | | | |
| **Conduct** | Low | 23 | 4.04 | 1.19 | F | 0.279 | 0.841 |
| | Intermediate | 30 | 4.07 | 1.64 | | | |
| | High | 53 | 4.15 | 1.45 | | | |
| | I Don't Know | 59 | 3.90 | 1.54 | | | |
| | **Total** | 165 | 4.03 | 1.48 | | | |
| **Hyperactive** | Low | 23 | 5.65 | 1.67 | F | 0.600 | 0.616 |
| | Intermediate | 30 | 5.70 | 1.21 | | | |
| | High | 53 | 5.79 | 1.57 | | | |
| | I Don't Know | 59 | 5.41 | 1.70 | | | |
| | **Total** | 165 | 5.62 | 1.57 | | | |
| **Peer** | Low | 23 | 6.09 | 1.28 | F | 0.201 | 0.895 |
| | Intermediate | 30 | 6.07 | 1.64 | | | |
| | High | 53 | 6.23 | 1.28 | | | |
| | I Don't Know | 59 | 6.02 | 1.58 | | | |
| | **Total** | 165 | 6.10 | 1.45 | | | |
| **Pre-social** | Low | 23 | 7.65 | 2.04 | F | 2.745 | 0.045 |
| | Intermediate | 30 | 6.80 | 1.79 | | | |
| | High | 53 | 7.98 | 1.87 | | | |
| | I Don't Know | 59 | 7.53 | 1.67 | | | |
| | **Total** | 165 | 7.56 | 1.84 | | | |
| **Total difficulties** (Emotional+ conduct+ hyperactivity+ peer) | Low | 23 | 16.43 | 4.40 | F | 1.751 | 0.159 |
| | Intermediate | 30 | 18.10 | 6.32 | | | |
| | High | 53 | 16.57 | 4.85 | | | |
| | I Don't Know | 59 | 15.36 | 5.67 | | | |
| | **Total** | 165 | 16.39 | 5.43 | | | |
| **Interval since the diagnosis** | | | | | | | |
| **Emotional** | 12 and less | 57 | 5.65 | 2.27 | F | 2.696 | 0.070 |
| | From 13 to 36 | 55 | 4.96 | 2.62 | | | |
| | 37 and more | 54 | 4.57 | 2.53 | | | |
| | **Total** | 166 | 5.07 | 2.50 | | | |
| **Conduct** | 12 and less | 57 | 4.09 | 1.52 | F | 0.407 | 0.666 |
| | From 13 to 36 | 55 | 4.13 | 1.55 | | | |
| | 37 and more | 54 | 3.89 | 1.36 | | | |
| | **Total** | 166 | 4.04 | 1.47 | | | |
| **Hyperactive** | 12 and less | 57 | 5.68 | 1.30 | F | 1.096 | 0.337 |
| | From 13 to 36 | 55 | 5.38 | 1.48 | | | |
| | 37 and more | 54 | 5.81 | 1.88 | | | |
| | **Total** | 166 | 5.63 | 1.57 | | | |
| **Peer** | 12 and less | 57 | 6.28 | 1.44 | F | 2.549 | 0.081 |
| | From 13 to 36 | 55 | 6.27 | 1.21 | | | |
| | 37 and more | 54 | 5.74 | 1.63 | | | |
| | **Total** | 166 | 6.10 | 1.45 | | | |
| **Pre-social** | 12 and less | 57 | 6.97 | 1.94 | F | 4.862 | 0.009 |

| | Medical Data | N | Mean | Std | Factor | Value | Sig. |
|---|---|---|---|---|---|---|---|
| | From 13 to 36 | 55 | 7.66 | 1.88 | | | |
| | 37 and more | 54 | 8.02 | 1.60 | | | |
| | **Total** | 166 | 7.54 | 1.85 | | | |
| **Total difficulties** (Emotional+ conduct+ hyperactivity+ peer) | 12 and less | 57 | 17.81 | 5.20 | F | 3.123 | 0.047 |
| | From 13 to 36 | 55 | 16.13 | 5.66 | | | |
| | 37 and more | 54 | 15.31 | 5.24 | | | |
| | **Total** | 166 | 16.44 | 5.44 | | | |
| **Suffering from other diseases** | | | | | | | |
| **Emotional** | Yes | 12 | 6.08 | 2.39 | t | 1.460 | 0.146 |
| | No | 154 | 4.99 | 2.50 | | | |
| **Conduct** | Yes | 12 | 3.58 | 1.08 | t | -1.107 | 0.270 |
| | No | 154 | 4.07 | 1.50 | | | |
| **Hyperactive** | Yes | 12 | 6.08 | 2.07 | t | 1.047 | 0.297 |
| | No | 154 | 5.59 | 1.53 | | | |
| **Peer** | Yes | 12 | 5.42 | 1.51 | t | -1.715 | 0.088 |
| | No | 154 | 6.16 | 1.43 | | | |
| **Pre social** | Yes | 12 | 6.92 | 1.51 | t | -1.203 | 0.231 |
| | No | 154 | 7.58 | 1.87 | | | |
| **Total difficulties** (Emotional+ conduct+ hyperactivity+ peer) | Yes | 12 | 17.50 | 4.38 | t | 0.700 | 0.485 |
| | No | 154 | 16.36 | 5.52 | | | |

**Annex (16): Scheffe test for differences between total difficulties in relation to interval since the diagnosis**

| Multiple Comparisons | | | | | | |
|---|---|---|---|---|---|---|
| Dependent Variable: Total difficulties | | | | | | |
| LSD | | | | | | |
| (I) Times | (J) Times | Mean Difference (I-J) | Std. Error | Sig. | 95% Confidence Interval | |
| | | | | | Lower Bound | Upper Bound |
| 12 and less | from13 to 36 | 1.67974 | 1.01545 | .100 | -.3254- | 3.6849 |
| | 37 and more | 2.49220* | 1.02023 | .016 | .4776 | 4.5068 |
| from13 to 36 | 12 and less | -1.67974- | 1.01545 | .100 | -3.6849- | .3254 |
| | 37 and more | .81246 | 1.02921 | .431 | -1.2198- | 2.8448 |
| 37 and more | 12 and less | -2.49220-* | 1.02023 | .016 | -4.5068- | -.4776- |
| | from13 to 36 | -.81246- | 1.02921 | .431 | -2.8448- | 1.2198 |
| *. The mean difference is significant at the 0.05 level. | | | | | | |

**Annex (17): Experts who evaluated the questionnaire**

| | |
|---|---|
| Dr. Bassam Abu Hamad | Al-Quds university |
| Prof. Yehia Abed | Al-Quds university |
| Prof. Abdalla El-Habil | Al- Azhar university |
| Dr. Khitam abu hamad | Al-Quds university |
| Dr. Mahmoud Shubair | Rantissi hospital |
| Dr. Salah Abu Shanab | Rantissi hospital |
| Dr. Reem Al- Aila | Al- Shifa hospital |
| Dr. Shafiq Alyan | Rantissi hospital |

## Absrtract in Arabic


**عنوان الدراسة: تقييم إدارة سرطان الأطفال في قطاع غزة**

**إعداد: شذا عبد الله محمد الهبيل**

**إشراف: د. بسام أبو حمد**

**الملخص**

**الخلفية والأهداف:**

يعتبر سرطان الأطفال مشكلة خطيرة تؤدي إلى زيادة معدلات الاعتلال والوفيات ويتزايد انتشاره في غزة وفي جميع أنحاء العالم. تهدف هذه الدراسة إلى تقييم الخدمات المقدمة للأطفال المصابين بالسرطان في مستشفى الرنتيسي التخصصي للأطفال بغزة.

**أساليب:**

تم تصميم الدراسة بطريقة التثليث: اشتملت على كل من النهج الكمي والنوعي، وتضمن النهج الكمي إجراء استبيان تمت مقابلته مع مقدمي الرعاية للأطفال المصابين بالسرطان (210) والتحقق من السجلات الطبية لهؤلاء الأطفال (210). تضمن النهج النوعي مقابلات مع 12 من المخبرين الرئيسيين. استخدمت الباحثة الحزمة الإحصائية للعلوم الاجتماعية الإصدار 25 لتحليل البيانات الكمية وطريقة الترميز المفتوح الموضوعية للبيانات النوعية.

**نتائج:**

وكشفت الدراسة أن متوسط عمر الأطفال المصابين بالسرطان بلغ 6.70 سنة وأن 52.9٪ منهم من الذكور. ما يقرب من نصف الأطفال مصابون بسرطان الدم وفقًا لما تم توثيقه في الملفات الطبية، وأشار حوالي 70.5٪ من المشاركين إلى أن سبب زيارتهم للمستشفى هو إجراء فحوصات مخبرية و 69٪ ذكروا للاستشارات. تلقى غالبية الأطفال المصابين بالسرطان (79.5٪) علاجًا كيماويًا في مستشفى الرنتيسي التخصصي للأطفال، بينما تلقى 58.6٪ دعمًا نفسيًا. أفاد ما يقرب من 58.1٪ من المشاركين بوجود نقص في الاختبارات التشخيصية و23.8٪ أفادوا بوجود نقص في الاختبارات المعملية في في مستشفى الرنتيسي التخصصي للأطفال. تلقى معظم الأطفال المصابين بالسرطان (84.3٪) العلاج والمتابعة في أكثر من مكان: المستشفيات المحلية في غزة والإحالة إلى خارج غزة، حيث تلقى 75.5٪ من الأطفال المصابين بالسرطان في هذه الدراسة العلاج الكيميائي خارج غزة. أظهرت نتائج الدراسة أن هناك فجوات في تقديم الخدمة بما في ذلك عدم كفاية الموارد البشرية مثل.

عدد محدود من أطباء أورام الأطفال، ولا يوجد جراحون متخصصون في الأورام، ولا خبراء تغذية. هناك بروتوكولات لإدارة سرطان الأطفال، ومع ذلك، فإن تطبيق هذه البروتوكولات يعوقه نقص الموارد. البنية التحتية لقسم أمراض الدم والأورام للأطفال مناسبة، والقسم مجهز بأحدث المعدات والتركيب المادي للمكان مريح ومناسب للأطفال. معظم الإحالات من الأطفال ناتجة عن العلاج المناعي مثل الأجسام المضادة وحيدة النسيلة والأسباب التشخيصية والجراحة والعلاج الإشعاعي وعادة ما تكون مقيدة بسياسات الاحتلال الإسرائيلي. هناك نقص في بعض الأدوية الأساسية مثل PEG– asparaginase و L–asparaginase و procarbazine و ريتوكسيماب والأجسام المضادة وحيدة النسيلة. كان متوسط الوقت بشكل عام لتلقي خدمات t من الدخول إلى الخروج من المستشفى هو 116.7 دقيقة. بلغ معدل اكتمال وثائق الملف الطبي 59.99٪. النسبة المئوية لمتوسط تفاعل المستخدم مع مزود الخدمة هي 81.7٪ والنسبة المئوية لمتوسط درجة الرضا عن الخدمات المقدمة 81.4٪. ومع ذلك، باستخدام استبيان نقاط القوة والصعوبات، أظهرت الدراسة أن 50٪ من الأطفال تم تصنيفهم على أنهم يعانون من مشاكل نفسية. أظهر الأطفال الذين يعمل آباؤهم، ولديهم دخل أفضل وتم تشخيصهم لأكثر من 3 سنوات، درجات أفضل في مقياس القوة والصعوبات، وكانت الفروق بينهم وبين مجموعاتهم المقابلة ذات دلالة إحصائية.

**الاستنتاج والتوصيات:**

من الضروري تعزيز سياسات إدارة سرطان الأطفال وتحسين مرافق التشخيص والموارد البشرية لإدارة سرطان الأطفال. من المهم تحسين المعلومات الصحية وسجل السرطان والدراسات البحثية المتعلقة بإدارة سرطان الأطفال وكذلك تعزيز الرعاية النفسية.