

**Deanship of Graduate Studies
Al-Quds University**



**Quality of Life among Children with
Cancer in Gaza Strip**

Mohammed Riad Ramadan Abu Reyala

M. Sc. Thesis

Jerusalem – Palestine

1440/2018

Quality of Life among Children with Cancer in Gaza Strip

Prepared by
Mohammed Riad Abu Reyala

BSc. of Nursing-Islamic University, Gaza, Palestine

Supervisor: Dr. Motasem Said Salah
Assistance Professor in Nursing Management

A Thesis Submitted in Partial Fulfillment of Requirements
for the Degree of Master of Pediatric Nursing / Faculty of
Health Professions / Al- Quds University

1440/2018

Al-Quds University

Deanship of Graduate Studies

Pediatric Nursing Program / Nursing Department



Thesis Approval

Quality of Life among Children with Cancer in Gaza Strip

Prepared By: Mohammed Riad Abu Reyala
Registration No.: 21612189

Supervisor: Dr. Motasem Said Salah

Master thesis submitted and accepted, Date: *22.1.2018*
The names and signature of examining committee members are as follow:

1- Head of committee: Dr. Motasem Said Salah

Signature: *[Signature]*.....

2- Internal Examiner: Dr. Abdulrahman Al Hams

Signature: *[Signature]*.....

3- External Examiner: Dr. Atif Ismail

Signature: *[Signature]*.....

Jerusalem – Palestine

1440/2018

Dedication

To my Father, who tirelessly struggled against the hurdles of this world, just to see his son attain the greatest gift of all.

To my world to my mother to whom I owe my life and success.

To my Wife, who kindly, remained by my side, with unending love, being patient, motivation and supporting.

To my sister for supporting me.

To my kids (Riad, Elaine, & Jwan) for their encouraging smiles.

To my friends

To my colleagues

To all children with cancer with my pray for them to (heal) have a good health.

And, to everyone who contributed to make this study a reality, thank you.

Mohammed Riad Abu Reyala

Declaration

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

Signed:

Mohammed Riad Abu Reyala

Date:...../...../.....

Acknowledgement

First and foremost, I thank Allah for helping me every moment during my study. I would like to thank many people who were a source of inspiration. Their wisdom and knowledge guided me throughout my research. I had the great fortune and pleasure to be supervised by Dr. Motasem Salah and Dr. Mohammed Al Jerjawy for their countless hours of reading, encouraging, guidance and most of all patience throughout the entire process. No matter how much I thank them, it still won't be enough to express the effort they put in.

I would also like to grant my deep appreciation to Dr. Hamza Abdeljawad for his endless support and his thoughtful suggestions and guidance. Sincere thanks to all academic and administrative staff of Al-Quds University for their support and guidance.

I cannot forget to mention the effort and support of the colleagues at Al-Rantessy Specialized Pediatric Hospital, and colleagues at European Gaza Hospital, for their active support for this research and in facilitation of data collection.

Special thanks to my friends and colleagues for their love, support, and endless help.

Abstract

Cancer is considered one of the major health problems worldwide, each year, more than 300,000 children are diagnosed with cancer. However, people now live approximately six times as long after their cancer diagnosis than 40 years ago. This has led to a long-term interest in the quality of life among children cancer survivors. So, the present study was conducted to assess quality of life among children with cancer in Gaza Strip. **Methods:** This descriptive, analytic, cross-sectional study included 122 children with cancer aged between 7 to 18 years. Data collected at El Ranteesy Specialized Pediatric Hospital and European Gaza Hospital. Quality of life data was collected by using the pediatric quality of life inventory (PedsQL 4.0 generic core scale), and pediatric quality of life cancer module scale (PedsQL 3.0 cancer module) to assess health-related quality of life. **Result:** The result showed that the mean percentage of quality of life score was (52.53%). The social function domain got the highest score (60.98%), and the lowest being emotional function domain (47.13%). Moreover, the overall mean percentage of health-related quality of life score was (48.55%). The nausea domain got the highest score (62.37%), and the lowest domain was procedural anxiety (24.38%). Finding showed that there is statistically significant difference between the children's families income regarding quality of life and health-related quality of life (p value = 0.011, 0.014; respectively). Moreover, there was statistically significant difference in the quality of life among children between their different number of family members (p value = 0.010). On the other hand, there is no statistically significant difference in the health-related quality of life among children between their different number of family members (p value = 0.231). **Conclusion:** The study concluded that the children with cancer in Gaza Strip had low level of quality of life and health-related quality of life. Moreover, the study showed that cancer has wide effects on children's ability to fully function in every field of their lives. It affects the physical, mental, school, and social well-being of children. **Recommendation:** In view of significant decrease in the quality of life domains among children with cancer in Gaza Strip, we emphasize on increasing efforts to avoid these negative impacts. This could be achieved by providing psycho-oncology services, enhancing pain management and anxiety reduction measurements, psychosocial support schedule for children and their families. Finally, guiding the society on how children with cancer should be treated through improving awareness and educational campaigns, and encouraging communication skills of healthcare givers.

Table of Contents

Dedication.....	I
Declaration.....	i
Acknowledgement.....	ii
Abstract.....	iii
Table of contents	iv
List of tables	vii
List of figures.....	ix
List of annexes.....	x
List of abbreviations	xi
CHAPTER (1) INTRODUCTION	1
1.1 Background.....	1
1.2 Research problem	2
1.3 Significant of the study.....	3
1.4 Purpose of the study	4
1.5 Specific objectives.....	4
1.6 Research questions	5
1.7 Context of study.....	5
1.7.1 Demographic characteristics of Gaza governorates.....	5
1.7.2 The socio-economic situation	6
1.7.3 Health care system	7
1.7.4 Cancer service providers.....	8
1.7.5 El Ranteesy Specialized Pediatric Hospital	8
1.7.6 European Gaza Hospital	8
1.7.7 Palestinian Health Information Center.....	9
1.8 Operational definitions	9
1.8.1 Child.....	9
1.8.2 Quality of life.....	9
1.8.3 Health-related quality of life (HRQOL)	9
1.8.4 Cancer	10
CHAPTER (2) LITERATURE REVIEW	11
2.1 Conceptual framework	11
2.2 Cancer.....	12
2.2.1 Background	12
2.2.2 Epidemiology of children cancer	12
2.2.3 Type of cancer.....	14
2.2.4 Risk factor for cancer.....	14
2.2.5 Treatment of cancer	15
2.2.6 Control of cancer.....	16
2.3 Quality of Life	17
2.3.1 Definition of QOL.....	17
2.3.2 Definition of HRQOL	18

2.3.3 Interest of studying QOL	19
2.3.4 Measurement of QOL	19
2.3.5 Pediatric Quality of Life Inventory (PedsQL 4.0 generic core scale) and PedsQL 3.0 cancer module	21
2.3.6 Domain of QOL (WHO, 2012).	22
2.4 Studies of QOL among children with cancer	24
2.4.1 International studies	24
2.4.2 Regional studies	31
2.4.3 National studies.....	32
CHAPTER (3) METHODOLOGY	34
3.1 Study design	34
3.2 Study population.....	34
3.3 Study setting	34
3.4 Study period.....	34
3.5 Sampling.....	35
3.6 Eligibility criteria.....	35
3.6.1 Inclusion criteria	35
3.6.2 Exclusion criteria	35
3.7 Study instruments	35
3.7.1 Pediatric Quality of Life Inventory (PedsQL 4.0 generic core scale).....	35
3.7.2 PedsQL 3.0 cancer module	36
3.8 Pilot study	36
3.9 Ethical and administrative consideration.....	37
3.10 Data collection.....	37
3.11 Data analysis.....	38
3.12 Limitation of the study	38
CHAPTER (4) RESULT &DISCUSSION OF THE STUDY	39
4.1 Result of the study	39
4.1.1 Socio-Demographic characteristics of the study sample	39
4.1.2 Health profile variables of the study sample.....	45
4.1.3 QOL among children with cancer in the GS.....	46
4.1.4 HRQOL among children with cancer in the GS	47
4.1.5 Differences in the QOL and HRQOL between male and female children in the GS	49
4.1.6 Differences in the QOL and HRQOL between children who receive their care in RSPH and in EGH	49
4.1.7 Differences in QOL and HRQOL between their different age groups of the children	50
4.1.8 Differences in the QOL and HRQOL between their different areas of residence ..	51
4.1.9 Differences in the QOL and HRQOL between their different families' income....	52
4.1.10 Differences in the QOL and HRQOL between their different fathers' education level.....	53
4.1.11 Differences in the QOL and HRQOL between their different mothers' education level.....	54

4.1.12 Differences in the QOL and HRQOL between different number of family members.....	55
4.1.13 Differences in the QOL and HRQOL between father’s working status	56
4.1.14 Differences in the QOL and HRQOL between mother’s working status	56
4.1.15 Differences in the QOL and HRQOL between their different diagnosis years of the disease	57
4.1.16 Differences in the QOL and HRQOL between those who have family history of cancer and who do not	58
4.2 Discussion of the study.....	58
4.2.1 Socio- economic and demographic characteristics	58
4.2.2 Health profile variables.....	63
4.2.3 QOL and HRQOL among children with cancer	64
CHAPTER (5) CONCLUSION AND RECOMMENDATIONS	67
5.1 Conclusion.....	67
5.2 Recommendation.....	68
5.3 Recommendation for further research	68
REFERENCES	69
ANNEXES	79

List of Tables

No.	Table	Page
Table 4.1	Sample distribution according to the participants' gender, hospital, and age groups	39
Table 4.2	Sample distribution according to the participants' fathers work, their mothers work, and number family members	44
Table 4.3	Sample distribution according to diagnosis years for the current disease and family history	45
Table 4.4	Mean percentage of each QOL domain among children with cancer in the GS	46
Table 4.5	Mean percentage of HRQOL among children with cancer in the GS	47
Table 4.6	Differences in the QOL and HRQOL between male and female children in the GS	49
Table 4.7	Differences in the QOL and HRQOL of life between children who receive their care in RSPH and in EGH	49
Table 4.8	Differences in the QOL and HRQOL between their different age groups of the children	50
Table 4.9	Differences in the QOL and HRQOL between their different areas of residence	51
Table 4.10	Differences in the QOL and HRQOL between their different families' income	52
Table 4.11	Differences in the QOL and HRQOL of life between their different fathers' education level	53
Table 4.12	Differences in QOL and HRQOL between their different	54

	mothers' education level	
Table 4.13	Differences in the QOL and HRQOL between different number of family members	55
Table 4.14	Differences in the QOL and HRQOL between father's working status	56
Table 4.15	Differences in the QOL and HRQOL between mother's working status	56
Table 4.16	Differences in the QOL and HRQOL between their different diagnosis years of the disease	57
Table 4.17	Differences in the QOL and HRQOL between those who have family history of disease and who do not	58

List of Figures

No.	Figures title	Page
Figures 2.1	Conceptual Framework Diagram	11
Figures 4.1	Sample distribution according to the participants' residence	40
Figures 4.2	Sample distribution according to the participants' families income	41
Figures 4.3	Sample distribution according to the participants' fathers level of education	42
Figures 4.4	Sample distribution according to the participants' mothers level of education	43

List of Annexes

No.	Annex title	Page
Annexes. 1	Map of Palestine	80
Annexes. 2	MOH Hospitals in Gaza Strip	81
Annexes. 3	Consent form	82
Annexes. 4	Socioeconomic and Demographic Information	83
Annexes. 5	Helsinki committee approval letter	84
Annexes. 6	Permission letter of ministry of health NO.1	85
Annexes. 7	Permission letter of ministry of health NO.2	86
Annexes. 8	Permission letter of ministry of health NO.3	87
Annexes. 9	Approval letter for using PedsQL core 4.0 and PedsQL 3.0 cancer Module	88
Annexes. 10	PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - English	90
Annexes. 11	PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - Arabic	92
Annexes. 12	PedsQL 3.0 cancer Module Version 3.0 - English	94
Annexes. 13	PedsQL 3.0 cancer Module Version 3.0 – Arabic	96
Annexes. 14	Time Table	98

List of Abbreviations

EGH: European Gaza Hospital

GS: Gaza Strip

HRQOL: Health- Related Quality of Life

MOH: Ministry Of Health

NGOs: Non-Governmental Organization

PedsQL: Pediatric Quality of Life Inventory

PHC: Primary Health Care

PHIC: Palestinian Health Information Center

PCBS: Palestinian Central Bureau of Statistics

QOL: Quality of Life

RSPH: Ranteesy Specialized Pediatric Hospital

UNRWA: United Nations Relief and Works Agency

WB: West Bank

WHO: World Health Organization

Chapter (1) Introduction

1.1 Background

Cancer is considered one of the major health problems worldwide with increasing incidence, financial load, social impact and a high mortality rate (Abed, et al, 2012). Cancer is an umbrella term used for many forms of the disease, however, they all share the common formation which involves the development of uncontrolled cells, which can affect any region of the human body including organs, tissues, bones and skin (WHO, 2017).

Children cancer is a major problem causing increase in morbidity and mortality rate in children. Internationally; child cancer is considered the second cause of death after congenital heart disease. In addition, over the past 20 years, there has been some increase in the incidence of children diagnosed with all forms of cancer; the global number of deaths from cancer will increase by nearly 80% by 2030, with most occurring in low- and middle-income countries (Center of Disease Control and Prevention-CDC, 2014).

Moreover, cancer is a leading cause of death for children and adolescents around the world, each year; more than 300,000 children are diagnosed with cancer – a disease that touches countless families and communities worldwide. With access to quality care, more than 80.0% of children with cancer can survive, living full and healthy lives. However, many children in low-income and middle-income countries do not receive complete care, and over 90.0% of childhood cancer deaths occur in low resource settings (WHO, 2018a).

In Palestine, cancer is the second leading cause of death where it represents (7.8%) of all cancer cases registered (Palestinian Health Information Center-PHIC, 2017). Moreover, children with cancer account for (6.5%) of the total patient with cancer in Gaza Strip (GS), males reported high number of children cancers, registered 119 cases which represents

(57%) of all children cancers while female cancer registered 91 cases which represents (43%) (MOH-Gaza, 2017a).

Cancer not only affects patients physically, but it may also impact the quality of life (QOL) of cancer survivors negatively (Osann, et al, 2014). Cancer can be physically and psychologically wearing both during treatment and even in survivorship. In cancer survivors, QOL encompasses physical, psychological, social, and spiritual well-being (Lavdaniti and Tsitsis, 2015). Recently, much attention has been paid to the negative impact of cancer and its treatment on the QOL in cancer children. Several reports have indicated that greater QOL impairment in children with cancer may be attributable to cancer symptoms, treatment side effects, and psychological distress (Pirri, et al, 2013).

Although curing cancer remains the main goal of cancer research, the interest of researcher concerning the QOL assessment in chronic diseases has increase constantly. There is now a great deal of information on physical, emotional and social aspects among cancer patients, most concerning the period around diagnosis and the subsequence years, with better detection and treatment. People now live nearly six times longer after their cancer diagnosis than was the case 40 years ago (Devance, 2010).

QOL is a broad concept used to emphasize an individual's emotional reaction to life occurrences, personality, life fulfillment and satisfaction with work and personal relationships; otherwise known as "well-being" (Theofilou, 2013).

1.2 Research problem

Children with cancer account for (6.5%) of the total patient with cancer in GS (MOH-Gaza, 2017a), this give the researcher an alarm to think deep to the consequences of that disease on the life of children affected.

In GS cancer is considered an exhausting, child suffering disease from three aspects; (1) the chronic nature of the disease itself in terms of frequent hospital visits, drug availability, side effects of drug and disease complication, (2) consequence of the disease on the QOL in patients regarding the physical, psychological, emotional, and social aspect, and (3) the Israeli's occupation siege that prevents patients from receiving care.

In fact, it was noticed that there is a gap about the evaluation of QOL among children with cancer in GS, in addition to unclear data for patients' needs and lack of studies about children cancer in GS. For this reason, the current study takes place to assess the QOL of children with cancer in GS. The researcher study the QOL for children with cancer for the first time in Palestine.

1.3 Significant of the study

The cancer patients group is one of the most vulnerable groups in any society, due to the pathogenicity of the disease, complexity of treatment, fatal expectation, social problems and systemic complication of the disease, all of which affect the QOL of the patients (Devance, 2010).

A great deal of attention and efforts should be directed toward children who suffering from cancer, because these children are in desperate need of health care, advising, follow-up, health education, and ongoing medical treatment, these efforts and actions should all be based on careful assessments of their needs and what fits their abilities and situation, to reduces the fatigue and prepare them to live a healthy life, life without worry or fear, because of that, our efforts should be primarily directed towards decreasing complication of this disease and improving the QOL for children, therefore this study will serve this trend.

Moreover, palliative care services in MOH were not provided as recommended by the WHO (Skaik, 2016). The GS contain gaps about cancer service, due to absence of clear guidelines and policies. That led to poor outcome, and low level of patients' satisfaction (Abu amer and Abed, 2012). That in turn affects the QOL for children cancer.

Because QOL is consider an entitlement for every person, it's a way for children happiness and civil peace, and because our children especially deserve the best, and since there are no studies conducted QOL among children with cancer in our society, these efforts have shed light on this subject, analyzing it from many important aspects, so by this study the researcher tries to reach many facts that were not discussed before regarding the QOL among children with cancer, thus gaining access to recommendations that will be useful in planning and assurance needs of those children.

1.4 Purpose of the study

The aim of this study is to assess the quality of life among children with cancer who live in Gaza Strip.

1.5 Specific objectives

- 1) To assess the level of QOL domains among children with cancer in GS.
- 2) To assess health- related quality of life (HRQOL) among children with cancer in GS.
- 3) To determine the relationship between socioeconomic, socio-demographic variables and QOL among children with cancer in GS.
- 4) To determine the relationship between socioeconomic, socio-demographic variables and HRQOL among children with cancer in GS.
- 5) To suggest recommendations that will improve QOL among children with cancer in GS.

1.6 Research questions

- 1) What are the effects of cancer on QOL of children?
- 2) What are the effects of cancer on HRQOL of children?
- 3) Do socioeconomic factors such as monthly income and parents employment affect the QOL of children?
- 4) Do demographic factors such as age and gender affect QOL of children?
- 5) Do demographic factors such as monthly income and parents employment affects the HRQOL of children?
- 6) Do demographic factors such as age and gender affect HRQOL of children?
- 7) What are the recommendations to improve the QOL among children with cancer in GS?

1.7 Context of study

1.7.1 Demographic characteristics of Gaza governorates

The occupied Palestinian territories consists of two geographically separated areas; West Bank (WB) and the GS. GS is a narrow zone of land bounded by Egypt at south, at west by the Mediterranean Sea, and at the east and north by the occupied territories in 1948 (Annex1). GS has a total area of 365 sq. km with 46 kilometers length and 5–12 kilometers wide and representing 6.1% of the total area of the occupied Palestinian territories, with estimated population of 2 million. GS is considered as one of the most overcrowded areas in the world with a population density of 5,154 inhabitants/sq.km (Palestinian Central Bureau of Statistics-PCBS, 2017).

According to the United Nations Relief and Works Agency (UNRWA) statistics in 2017, the total number of registered Refugees in GS constitutes about 1.3 million Palestinians of the total population (UNRWA, 2016). GS is geographically divided into five governorates: Gaza, Mid-Zone, Khan-Younis, Rafah, and North Gaza (Palestinian Water Authority, 2013).

1.7.2 The socio-economic situation

The economic status in the GS is very low, and suffers from continuous pressure caused by long-term siege imposed by Israelis' occupation for more than 12 years. Because of this siege, a significant increase in poverty rates has occurred in GS from 38.8% in 2011 to 53% by the end of 2017 (United Nations Office for the Coordination of Humanitarian Affairs - OCHA, 2018).

In GS, there are three main types of localities of residence; urban, rural and camps. Around 70% of the total population is refugees. Moreover, the socio-economic status of the GS is severely suppressed by high population density, limited land access, effects of Israeli occupation military operations and restriction on labor and trade access across the border by the siege imposing since 2007. These factors have dramatically increased the rates of unemployment and poverty in GS. The average unemployment rate is well over 41.7 % – one of the highest in the world, according to the World Bank. The number of Palestine refugees relying on UNRWA for food aid has increased from fewer than 80,000 in 2000 to almost one million today (UNRWA, 2016).

These numbers create long term adverse effect on all aspect of life in GS, and it affects the health condition, QOL among all Gaza's people, and those negative effects peak when it comes to patients. This increase imposes more challenges and load over health care providers in GS.

1.7.3 Health care system

The healthcare system in Palestine is complex, unique and strongly influenced by the Israeli occupation. The consequences of the closures and separation imposed a great challenge for the MOH by creating obstacles regarding the accessibility to health care services and affected the unity of the health care system in all Palestinian governorates (UNRWA, 2016).

There are four main health care providers; MOH, UNRWA, Non-Governmental Organization (NGOs), and the private sector. With such multitude of service providers, there are numerous challenges in providing a well-coordinated, standardized health service provision during normal times and frictions are deemed to exacerbate during emergencies (WHO, 2014). UNRWA provides health-care services to the vast majority of the over 1.3 million Palestine refugees in GS through 22 medical centers, providing Primary health care (PHC), secondary and tertiary health care services (UNRWA, 2016).

MOH is the main health care provider in the governorates; it provides PHC, secondary and tertiary services for the whole population. The number of hospitals owned by MOH in GS is 13 hospitals with capacity 1664 beds (MOH- Ramallah, 2017b) (Annex 2). It provide advanced medical services through referring patients to the neighboring countries and other private and NGO healthcare facilities. MOH has been seriously affected by the financial crisis being experienced by the Palestinian Authority. In fact, there have been reductions in the numbers of patients being referred outside the occupied Palestinian territory for specialized treatment and there have been growing and substantial shortages of medicines and disposables (WHO, 2018b).

1.7.4 Cancer service providers

MOH providers service for cancer patients through two hospitals that provide therapeutic care; European Gaza Hospital (EGH) and El Ranteesy Specialized Pediatric Hospital (RSPH). In each medical sites, patients are seen in outpatient departments or admitted to inpatient departments. In addition, there are two histopathology laboratories at Al-Shifa hospital and EGH.

1.7.5 El Ranteesy Specialized Pediatric Hospital

RSPH is the only specialized pediatric in G.S, providing care to children with chronic disease. It was constructed in 2003, and the building was ready for work in 2006, it is located in Al Nasser Street in Gaza City. It has different department that provide several services for the patients, one of them is the oncology unit which was built in 1998 in al Nasser Pediatric Hospital, and then transferred to RSPH in April 2008. The oncology unit services extended from North to the South of Gaza for different types of cancer and it consists of five rooms; three isolation rooms with one bed and two with five beds for children (MOH-Gaza, 2013).

1.7.6 European Gaza Hospital

EGH located in Khan-Younes governorate at the southern area of GS. The hospital was established in 1993 on an area of 65.000 square meters and started to provide health care services to people on 15 of July 2000. It is considered as a referral center and provides secondary care for Rafah and Khan Yonis governorates. EGH provides different medical specialties, including medical and surgical services with a total beds capacity of 246 beds and includes computerized network system with quality care for patients, in addition, it offers specialist health services to people from all Gaza Governorates. The oncology department was established in year 2000; it serves 40% of cancer cases (adult and adolescent) in GS and contains 14 beds (MOH-Gaza, 2013).

1.7.7 Palestinian Health Information Center

PHIC is a department within the Palestinian MOH, is responsible for preparing the health information and providing health indicators on the Palestinian health situation. The mission of the Palestinian health information center is to build a national health information system that utilizes the latest technology in data collection, archiving, analyzing, dissemination and distribution to make information available for access by healthcare providers, institutions, students, researchers and parties interested in health issues (MOH-Ramallah, 2017).

1.8 Operational definitions

1.8.1 Child

According to the convention on the right of the child, a child means every human being below the age of 18 years, unless under the law applicable to the child, majority is attained earlier (UNICEF, 2014).

1.8.2 Quality of life

QOL is a broader concept which consists of both medical and psychosocial aspects, including activities of daily living, instrumental activities, psychological well-being, social functioning, perception of health status, and overall satisfaction with life (Chaturvedi and Muliya, 2016).

Operationally, QOL refer to the response of children with cancer on the domains of the QOL as measured by the score obtained using PedsQL- 23 instrument.

1.8.3 Health-related quality of life (HRQOL)

HRQOL is defined as the functional effect of a medical condition and/or its consequent therapy upon a patient, and includes ‘physical and occupational function, psychological

state, social interaction, somatic sensation, perceptions of health, fitness, life satisfaction and well-being' (International Society for Quality of Life Research-ISOQOL, 2015).

Operationally, HRQOL refer to the response of children with cancer on the domains of the HRQOL as measured by the score obtained using HRQOL cancer module - 27 instruments.

1.8.4 Cancer

Cancer is a generic term for a large group of disease that can affect any part of the body. Other terms used are malignant tumors and neoplasm; defined as the rapid creation of abnormal cells that grow beyond their usual boundaries, which can then invade adjoining parts of the body and spread to other organs. This process is referred to as metastasis, which is the major cause of death from cancer (WHO, 2017).

Chapter (2) Literature review

2.1 Conceptual framework

A conceptual framework is a basic element in scientific research. It connects and clarifies the relationship between the dependent and the independent variable. The conceptual framework of the study as shown in figure 2.1, illustrates variable that interact and affect the QOL among children with cancer.

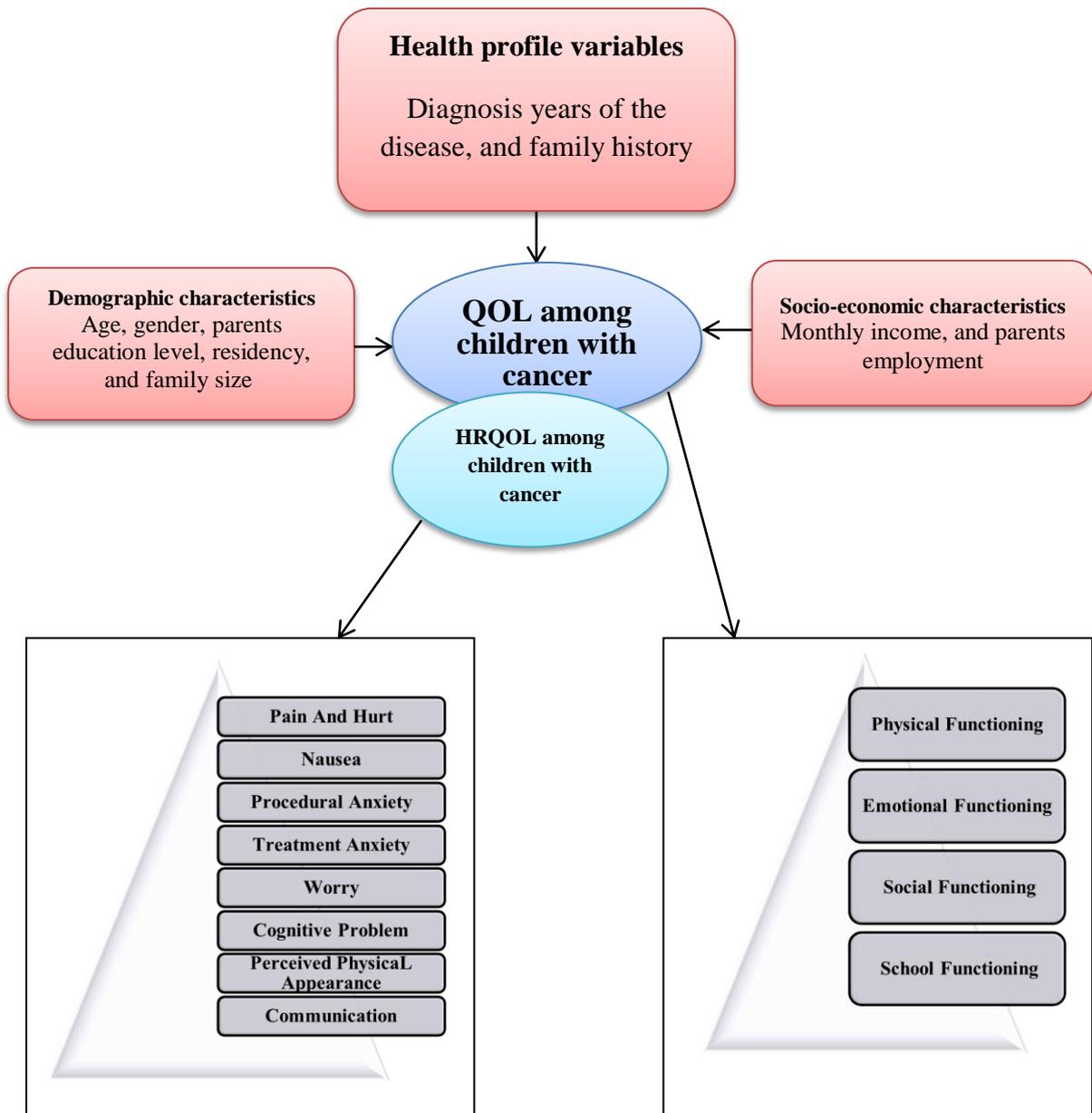


Figure (2.1) Conceptual Framework Diagram

2.2 Cancer

2.2.1 Background

Cancer is a generic term for a large group of diseases characterized by the growth of abnormal cells beyond their usual boundaries that can then invade adjoining parts of the body and/or spread to other organs. Other common terms used are malignant tumors and neoplasms. Cancer can affect almost any part of the body and has many anatomic and molecular subtypes, each require specific management strategies (WHO, 2018c).

Moreover, cancer is the name given to a collection of related diseases. In all types of cancer, some of the body's cells begin to divide without stopping and spread into surrounding tissues (National Cancer Institute-NCI, 2015).

2.2.2 Epidemiology of children cancer

Cancer is a disease that touches countless families and communities in all regions of the world. Each year, more than 300,000 children are diagnosed with cancer. However, many children in low-income and middle income countries do not receive or complete care, and over 90.0% of childhood cancer deaths occur in low resource settings (WHO, 2018a).

According to International Association of Cancer Registries-IACR, (2015) the reported worldwide incidence of childhood cancer is increasing from 165,000 new cases annually to 215,000 cases for children 14 years and younger and 85,000 new cases for 15-19 year olds. Many more remain uncounted and unreported due to a lack of childhood cancer registries in a large number of countries.

There were 762 new childhood cancer registrations in the five years between 2010 and 2014, giving an overall New Zealand child cancer incidence rate of 167 per million per year (Ballantine, 2017). In the Ireland, 137 cases of cancer were diagnosed per year among children under age 15 during 1994-2014. Average annual numbers have risen from 117 per

year during 1994-2000 to 163 per year during 2008-2014 (National Cancer Registry Ireland, 2017). In addition, American cancer society (2017) estimated that 10,270 new cancer cases will be diagnosed among children 0 to 14 years of age in the United States in 2017.

In the Arab World, Saudi Health Council (2014) reported the total of 822 cancer cases were diagnosed among children aged between 0 and 14 years accounted to 5.2% of the total number of cancers in Saudi Arabia. Another study based in Syria showed that a children with cancer account for 10% of all cancer cases, 1760 were children. Unfortunately, it is expected that 800 of them will not survive. In 2013, there were about 2500 -3000 children diagnosed with cancer. The most common types of cancer among children 0- 15 years old are leukemia and brain tumors (Faris, et al, 2016).

In Palestine, MOH reported that children with cancer represent 7.8% of all cancer cases registered in Palestine, Leukemia is classified first with a rate of 30.2% followed by brain and nervous system cancer with a rate of 18.5% of the total cancer cases registered in Palestine, lymphoma cancer comes in third with a rate of 7.4%. Multiple myeloma cancer comes in fourth by 5.8% followed by lymph nodes cancer with a rate of 4.2% of the total cancer cases registered by the children in Palestine. These five types of cancer represent about two-thirds of the cancer cases recorded among children in Palestine, with a rate of 66.1% (MOH-Ramallah, 2016).

The mortality rate among children with cancer compared with all cancer cases in Palestine reached 3.8%. Brain cancer is ranked as the first of cancers leading to death among Palestinian children with a rate of 43.9% of all cancer deaths among children in Palestine. Leukemia, meanwhile, is ranked the second with a rate of 26.8% in which these two types

of cancer form 70.7% of cancer deaths among children in Palestine (MOH-Ramallah, 2016).

Here in GS, children with cancer accounted for 6.5% of the total patient with cancer, males reported high number of children cancers, registering 119 cases which represents 57% of all children cancers while female cancer was registered 91 cases which represents 43% (MOH-Gaza, 2017a).

2.2.3 Type of cancer

Cancer is not just disease but many diseases. There are more than 100 different types of cancer. Most cancers are named for the organ or type of cell in which they started (NCI, 2015). Leukemia (cancer of the blood) is the most commonly diagnosed cancer within children. Brain tumors are the most common form of solid malignancy and lymphoma (cancers within the lymphatic system) and neuroblastoma (cancer of specialized nerve cell) are some of the most common forms of cancers which children develop (Dommett, et al, 2012). It must be acknowledged that children may develop cancers which usually affect adults but this happens very rarely (Davidoff, 2010).

2.2.4 Risk factor for cancer

WHO (2017) reported that cancer arises from the transformation of normal cells into tumor cells in a multistage process that usually progresses from a pre-cancerous lesion to a malignant tumor.

These changes are the consequence of the interaction between a person's genetic factors and three categories of external agents, including:

Physical carcinogens: such as ultraviolet and ionizing radiation.

Biological carcinogens: such as infections from certain viruses, bacteria, or parasites.

Chemical carcinogens: such as aflatoxin (a food contaminant), and arsenic (a drinking water contaminant).

Here in Gaza, Elnuweiry, (2015) conducted a study to identify the main risk factors for pediatric cancer among children in Gaza Governorates, the results which showed that risk factors associated with pediatric cancer were as follows; child education level, child father age, medication giving during gestational period, exposure to Ultrasound during gestational period, family cancer history and degree to relevant to child, daily beverage intake and additives in drinking, in addition to association between family history of smoking and maternal exposure to passive smoking or aerosol while pregnant.

2.2.5 Treatment of cancer

According to NIC (2017) there are many types of cancer treatment. The types of treatment that a child with cancer receives will depend on the type of cancer and how advanced it is. Moreover, cancer treatment require a careful selection of one or more intervention such as:

Surgery: Is a procedure in which a surgeon removes cancer from the body.

Radiation Therapy: Is a type of cancer treatment that uses high doses of radiation to kill cancer cells and shrink tumors.

Chemotherapy: Is a type of cancer treatment that uses drugs to kill cancer cells.

The goal of treatment is to cure the disease or significantly prolong life while improving the patient's QOL by the following:

2.2.5.1 Cure among early detectable cancers

There are many type of cancer, such as cervical cancer and oral cancer that have high cure rates on early detection and prompt treatment according to best practices (WHO, 2017).

2.2.5.2 Potential for cure of some other cancers

Some cancer types, such as leukemia and lymphomas in children, can have high cure rates if appropriate treatment is provided even when cancerous cells have already metastasized to other areas of the body (WHO, 2017).

2.2.6 Control of cancer

Cancer control aims to reduce the incidence, morbidity and mortality of cancer and to improve the QOL of cancer patients through the systemic implementation, WHO (2018a) determined four component of cancer control as follow:

2.2.6.1 Prevention

Prevention of cancer, especially when integrated with the prevention of chronic disease and other related problem, offers the greatest public health potential and the most cost effective long-term method of cancer control. Now there is sufficient knowledge to prevent around 40% of all cancer. Most cancerous disease are linked to unhealthy diet and infectious disease (WHO, 2018a).

2.2.6.2 Early detection

When identified early, cancer is more likely to respond to effective treatment and result in a greater probability of survival, less suffering and often less expensive and less intensive treatment. Furthermore, there are two strategies for early detection, early diagnosis, and screening:

Early diagnosis: Early diagnosis, often including the families' awareness of early signs and symptoms, leading to consultation with a healthcare provider, followed by prompt referral for confirmation of diagnosis and initiation treatment.

Screening: National or regional screening of symptomatic and apparently healthy individuals to detect pre-cancerous lesion or an early stage of cancer, and to arrange referral for diagnosis and treatment (WHO, 2018a).

2.2.6.3 Treatment

Treatment aims to cure disease, prolong life, and improve the quality of remaining life after the diagnosis of cancer is confirmed by the suitable available procedures. The most effective and efficient treatment is related to early detection programs and follows evidence-based standards of care. Children patients can benefit either by cure or by prolonged life, in cases of cancers that although disseminated are highly responsive to treatment, including acute leukemia and lymphoma. This component also addresses rehabilitation aimed at improving the QOL of patients with impairments due to cancer (WHO, 2018a).

2.2.6.4 Palliative care

Palliative care relieves symptoms caused by cancer and improves the QOL of children patients and their families. Not all children with cancer can be cured, but relief of suffering is possible for everyone. This is principally true when patients are in advanced stages and have a very low chance of being cured, or when they are facing the terminal phase of the disease. Because of the emotional, spiritual, social and economic consequences of cancer and its management, palliative care services concentrating the needs of patients and their families, from the time of diagnosis, can improve QOL and the ability to cope effectively (WHO, 2018a).

2.3 Quality of Life

2.3.1 Definition of QOL

There is no universal conventional definition of QOL. Some argue that there is more disagreement on what QOL means than on any other concept in medical, social, and

psychological research. QOL may be defined based on how an individual measures the goodness of different aspects of their life. These assessments include one's emotional reactions to life events, disposition, sense of fulfillment and satisfaction with personal relationships and work (Theofilou, 2013). Another definition encompasses the person's level of functioning and overall satisfaction and well-being of their life (Lavdaniti and Tsitsis, 2015).

QOL is a broad multidimensional concept that considers a person's physical, emotional, social, and spiritual well-being (Barcaccia, 2013). In addition, Chaturvedi and Muliya, (2016) defined QOL as a broader concept which consists of both medical and psychosocial aspects, including activities of daily living, instrumental activities, psychological well-being, social functioning, perception of health status and overall satisfaction with life.

2.3.2 Definition of HRQOL

Measures of HRQOL has evolved since 1980 and include those aspects of QOL that can be clearly shown to affect health—either physical or mental (CDC, 2016). Furthermore, measures of HRQOL provide a broad view of child health, including aspects of perceived health, health behavior, and well-being. Therefore, HRQOL has the potential to express the health of children in the general and specific population more systematically than conventional health measures and provide better identification of specific groups with high rates of unrecognized conditions, social and emotional problems, and poor well-being and functioning (Simon, et al, 2008).

HRQOL can be defined as “how well a person functions in their life and his or her perceived wellbeing in physical, mental, and social domains of health (Hays and Reeve, 2010). Moreover, HRQOL is a multidimensional instrument that includes the comprehension of the positive and the negative aspects of different dimensions such as the

physical, emotional, cognitive and social domains, as well as pain/discomfort (Haddou, et al, 2016).

Foundation Health Measures, (2010) defined HRQOL as a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact health status has on QOL.

2.3.3 Interest of studying QOL

QOL is considered a significant factor that combines measures of human needs with subjective well-being or happiness. QOL is proposed as a multiscale, multi-dimensional concept that contains interacting objective and subjective elements. Moreover, QOL relates to the opportunities that are provided to meet human needs in the forms of built, human, social, and the policy options that are available to enhance these opportunities (Costanza, et al, 2008).

Focusing on QOL as an outcome can bridge boundaries between disciplines and social, mental, and medical services. Moreover, measuring QOL can help in determining the burden of preventable disease, injuries and disabilities, and can provide valuable new insights into the relationships between QOL and risk factors; also, it will help in monitoring progress in achieving the nation's health objectives (CDC, 2016).

2.3.4 Measurement of QOL

There is an increasing need for international standards to measure QOL in a modus that allows comparison across cultures. Briefly, the international standards have to be applicable to individual cultures. The known differences between Western and Eastern cultures may be reflected in the QOL measurement results (Ayoub and Hijjazi, 2013).

QOL is multidimensional and highly subjective, for this reason, its measurement is difficult. QOL questionnaires are also called tools, or instruments. They measure multiple characteristics signified as scales or domain and consist of questions identified as items. QOL measurement tools are quantitative measure which allow comparable, reproducible, responsive and effective functional health status determination to be made. Measurement of QOL is done by using either preference based or functions based instruments. Additionally, preference based instrument evaluate the value placed by patient on their QOL while function based tools use items to grade the degree of patients knowledge while performing vision- related tasks (Aspinall, et al, 2007).

2.3.4.1 Types of QOL measurements

Fryback (2010) reported that there are two different types of measures in the assessment of QOL; generic and specific instruments

- **Generic measure**

Generic measures are means by which a very wide collective of aspects is examined, generic QOL measurement is ought to cover physical, emotional and social functioning as well as self-perception of health and satisfaction, the use of generic measurements is mainly comparative, observing the differences between patients, health statuses, diseases, and treatments (Fryback, 2010).

- **Specific measure**

Specific measurements are useful for observing any disease or population, particular phenomenon and response to specific treatments. These concentrate on a problem within a patient group such as pain, fatigue, and physical functioning (Fryback, 2010).

2.3.5 Pediatric Quality of Life Inventory (PedsQL 4.0 generic core scale) and PedsQL 3.0 cancer module

The PedsQL measurement model was developed by Dr. James Varni. It is a modular approach to measuring QOL in children and adolescents. The PedsQL consists of brief, practical, generic core scales suitable for use with healthy school and community populations, as well as with pediatric populations with acute and chronic health conditions. PedsQL condition-specific modules complement the generic core scales for use in designated clinical populations (Varni, et al, 2002).

The PedsQL 4.0 generic core scales are population QOL measures that have demonstrated good reliability and construct validity in a wide variety of general. Moreover, scales instrument consists of the following 4 domains: (1) physical functioning, (2) emotional functioning, (3) social functioning, and (4) school functioning. It includes formats for typically developing children and adolescents 2 to 18 years old (parent-proxy report) and 5 to 18 years old (self-report). The participants evaluated how often a specific problem occurred in the past month, a 5-point Likert scale (0 = never, 1 = almost never, 2 = sometimes, 3 = often, 4 = almost always) for children 7 to 18 years and for the parents of all ages (Varni, et al, 2001 and Varni, et al, 2003).

The PedsQL 3.0 cancer module was designed to measure pediatric cancer specific-HRQOL. The 27-item multidimensional PedsQL 3.0 cancer module acute version contains 8 scales: pain and hurt (2 items), nausea (5 items), procedural anxiety (3 items), treatment anxiety (3 items), worry (3 items), cognitive problems (5 items), perceived physical appearance (3 items), and communication (3 items). Similar to the PedsQL 4.0 generic core scale, a 5-point Likert scale is used for children 7 to 18 years old and for parents of children of all ages (Varni, et al, 2001 and Varni, et al, 2003).

2.3.6 Domain of QOL (WHO, 2012).

2.3.6.1 Domain I - Physical domain

2.3.6.1.1 Pain and discomfort

This domain explores unpleasant physical sensations experienced by a person and the extent to which these sensations are distressing and interfere with life. In fact, changes in levels of pain may be more distressing than the pain itself. Even when a person is not actually in pain, either through taking drugs or because the pain is by its very nature on and off, his/her QOL may be affected by the persistent threat of pain. It is acknowledged that people respond to pain differently, and differing tolerance and acceptance of pain is likely to affect its impact on QOL.

2.3.6.1.2 Energy and fatigue

This component discovers the energy, enthusiasm, and strength that a person has in order to perform the necessary tasks of daily living, in addition to other chosen activities such as recreation. This may range from reports of disabling exhaustion to adequate levels of energy, to feeling really alive.

2.3.6.1.3 Sleep and rest

This facet concerns how much sleep and rest, and problems in this area, affect the person's QOL. Sleep problems might include difficulty going to sleep, waking up during the night, waking up early in the morning and being unable to go back to sleep and lack of refreshment from sleep.

2.3.6.2 Domain II – Psychological domain

2.3.6.2.1 Positive feelings

This aspect examines how significantly a person experiences positive feelings of contentment, balance, peace, happiness, hopefulness, joy and enjoyment of the good things

in life. A person's feelings about the future are seen as an important part of this aspect. For many respondents this facet may be considered as synonymous with QOL.

2.3.6.2.2 Thinking, learning, memory and concentration

This represents the person's view of his/her thinking, learning, memory, concentration and ability to make decisions. This includes the speed of thinking and clarity of thoughts.

2.3.6.2.3 Self-esteem

This facet explores how a person feels about oneself. This powerfulness ranges from feeling extraordinarily positive about oneself to extremely negative. Here, a person's sense of worth as an individual is explored. The aspect of self-esteem is concerned with a person's feeling of self-efficacy, satisfaction with oneself and control.

2.3.6.2.4 Body image and appearance

This aspect examines the person's view of his/her body. Whether the appearance of the body is seen in a positive or negative way is encompassed in this aspect. Additionally, the attention is on the person's satisfaction with the way he/she looks and the effect it has on his/her self-perception.

2.3.6.2.5 Negative feelings

This section concerns how significantly a person experiences negative feelings, including sadness, guilt, despair, nervousness, anxiety and a lack of pleasure in life. The section includes a consideration of how distressing any negative feelings are and their impact on the person's QOL.

2.3.6.3 Domain III - Social relationships domain

2.3.6.3.1 Personal relationships

This facet consists of the ability and opportunity to love, to be loved and to be close with others both emotionally and physically. The extent to which people feel they can share moments of both happiness and distress with loved ones.

2.3.6.3.2 Social support

This includes how supported the person feels and whether he/she is receiving adequate reassurance and encouragement from family and friends.

2.4 Studies of QOL among children with cancer

2.4.1 International studies

A study was conducted to assess differences in QOL, distress behavior, and fatigue among children and adolescents. Three instruments including pediatric QOL, distress behaviors, and multidimensional fatigue scales were administered for 150 participants, all participants were given a diagnosis of cancer, ranged in age from 7 to 18 years, and had no developmental delay or mental illness. Results showed that adolescents aged 16 to 18 years reported lower school functioning and experienced more general and sleep/rest fatigue. Fatigue and distress behaviors were associated with a poorer QOL. Diagnosis at a younger age, greater time since diagnosis, and family structure were associated with a better QOL. General fatigue, relationship distress, family structure, and time since diagnosis were significant predictors of QOL (Pan, et al. 2017).

A study was conducted at Hacettepe University Pediatric Oncology Unit in Turkey, to evaluate the HRQOL and the effect of associated factors such as cancer type, treatment strategies, sex, age, and parental factors in pediatric cancer survivors and make a comparison with healthy children for 302 survivors without major mental or motor deficit

and 272 healthy controls of 8 to 18 years of age were enrolled to this study, the results of this study were that female survivors had reported significantly worse QOL in physical and emotional subscales of PedsQL than male survivors. Parents of the control group reported better results in school subscales and social functioning subscales than parents of survivor group. Significantly better scores of physical functioning subscale were observed in the survivors whose parents are university graduate than those whose parents are primary school graduates. The survivors with central nervous system tumors had reported lower scores in the social, emotional, physical, and school functioning subscales of PedsQOL than patients with non-Hodgkin and Hodgkin lymphoma (Yağc-Küpelı, et al, 2012).

Chung et al, (2012) examined the predisposing factors to the QOL of Hong Kong Chinese childhood cancer survivors, with 153 survivors (9-16 years of age) during follow-up at the oncology outpatient clinic showed that depressive symptoms are a strong predictor of QOL in childhood cancer survivors and that systematic screening of this population is important. It is essential for healthcare professionals to develop, plan, and evaluate interventions with the aim of alleviating depressive symptoms for childhood cancer survivors so as to enhance their QOL.

Vlachioti et al, (2016a) conducted a study to evaluate the QOL of children and adolescents with any type of cancer in all phases of their treatment. Fifty-six newly diagnosed patients with malignancy and hospitalized in a Pediatric Hematology-Oncology Unit in Athens were included in the study; the result of this study was that, children and adolescents with any kind of cancer have better QOL scores at the end of their treatment, and when they are supported by their family.

Avoine-Blondn et al, (2016) undertook a study to describe the domains of QOL in the context of primary peritoneal cancer in oncology, according to the perceptions of

professional caregivers, by using semi-structured interviews were conducted with a random sample of 20 professional caregivers from the division of Oncology at Le Centre Hospitalize Universities in Canada. The caregivers were asked about their perceptions about the QOL of the children they have cared for in this context, the result of this study was that, caregivers recount the regard that should be accorded to maintaining well-being and a sense of fun, as well as fostering the child's abilities, taking into account of the progression of the disease, and to fulfilling his/her needs; especially social ones. The results also demonstrated that all domains were positively referred to by professional caregivers.

A study was conducted in three large pediatric cancer centers in Philadelphia to describe QOL and its relationship to symptom distress. Associations were evaluated using linear mixed-effects models adjusting for sex, age, cancer type, intervention arm, treatment intensity, and time since disease progression. The result of this study was that the total QOL score was median level. 13 out of 24 symptoms were independently associated with reductions in overall or domain-specific QOL. Patients commonly reported distress from two or more symptoms, corresponding to larger QOL score reductions. Neither cancer type nor time since progression, treatment intensity, sex or age was associated with QOL scores in multivariable models. Among 25 children completing surveys during the last 12 weeks of life, 11 distressing symptoms were associated with reductions in QOL (Rosenberg, et al, 2016).

A study was conducted to assess the QOL of adolescents with cancer and survivors of childhood cancer as well as the effect of various demographic factors upon it. The sample of the study included 82 adolescents aged 13–20 years who had been diagnosed with any type of cancer. Minneapolis–Manchester quality questionnaire of life instrument was used, the result of this study was that the QOL of adolescent patients did not significantly change

during treatment and they showed a satisfactory QOL. Boys scored higher than girls in psychological function and in body image, the studied population scored a sufficient QOL, especially survivors of childhood cancer ones. Moreover, their QOL seemed to be influenced by the stage of treatment, the type of cancer, sex, age, family support, and education (Vlachioti, et al, 2016b).

A study was conducted to assess self-perception and QOL of adolescents during or up to three months after adjuvant treatment for a primary malignant bone tumor, 10 adolescent patients (median age of 15 years) were included. Every patient was matched with two healthy peers. Participants completed the Dutch Version of the Self Perception Profile of Adolescents to measure self-perception and the (KIDSCREEN-52) questionnaire for QOL. For both instruments, normative data were available, the result showed that adolescents with a primary malignant bone tumor during, or up to three months after adjuvant treatment had lower scores on QOL (Van Riel, et al, 2014).

Eilertsen et al, (2011) explored subjective and proxy reported QOL in children and adolescents surviving cancer three years after diagnosis, compared with healthy controls. This was done by using PedsQL scale and KINDL QOL questionnaires for 50 children and adolescents diagnosed with cancer between 1993 and 2003 in Norway. The results showed that adolescents surviving brain tumors or those with late effects reported lower QOL. Additionally, parents generally report a poorer QOL for their children surviving cancer and a greater number of QOL domains experienced as problematic compared with parent controls.

In Brazil, a study was conducted to examine the different dimensions of HRQOL, fatigue, and the relationships between fatigue and HRQL in hospitalized children and adolescents with cancer, by using PedsQL (Generic and Cancer module) and Multidimensional Fatigue

Scale. The results showed that children and adolescents with cancer had problems with fatigue in the three dimensions (general, sleep/rest, cognitive) that affected HRQOL in both the generic and cancer modules. Significant differences were found in the physical, emotional, and school functioning, but not in social functioning, between those with and without fatigue (Nunes, et al, 2017).

Chirivella et al, (2009) assessed the HRQOL of children with cancer in Hyderabad, India by using physician proxy assessments for 45 child and their physicians. The results showed that most of the children had acute lymphoblastic leukemia. In addition, there were no differences in patterns observed between cancer types for the child's HRQOL, but there was wide variation in the total HRQOL scores among the children. This variation was more evident in certain aspects of children's life, such as emotion and pain.

A study was conducted in Kermanshah-Iran to compare the QOL, anxiety and depression in children with cancer and healthy children, using (WHOQOL-BREF), Children's Depression Scale (CDS) and the Revised Children's Manifest Anxiety Scale (RCMAS) for 60 child with cancer and the result that raised was that there were significant differences between the cancer and healthy children in terms of all coping styles. Moreover, the mean scores of depression and anxiety of cancer children exceeded those of healthy children, while the mean score of cancer children's QOL was (45.2%) lower than that of healthy children (Nazari, et al, 2017).

Fakhry et al, (2013) examined the effects of cancer on HRQOL from diagnosis to remission and the end of life, using Medline and PsycINFO for articles published from 2002 to 2011 for 29 studies specifically addressing HRQOL. This study showed that children who are newly diagnosed with cancer and are undergoing treatment or are terminally ill have impaired HRQOL and survivors of childhood cancer have high

HRQOL. In addition, the demographic differences, cancer types and treatment regimens, all significantly influence the negative impact of cancer on patients' HRQOL.

A study was conducted to describe HRQOL changes among children and adolescents during the first 6 months of hematopoietic stem cell transplant (HSCT) recovery and estimate the associations of demographic factors, diagnosis, transplant information, and symptoms with HRQOL in a pediatric teaching institution in the southern United States. This was done by using Memorial Symptom Assessment questionnaire and the Peds QOL Cancer Module for 23 children who received an allogeneic HSCT and showed that HRQOL fluctuated during the study with the lowest HRQOL noted at 1 month post-HSCT and the highest HRQOL noted at 4 months post-HSCT. However, no significant differences in HRQOL were noted among demographic, diagnosis, or transplant factors (Rodgers, et al, 2015).

In North India a study has been conducted to assess HRQOL of pediatric cancer patients and their parents by using Lansky play performance scale and health utility index-2 (HUI-2) for 57 children were followed up after 4 months after therapy, and using (WHOQOL-BREF) for their parents. 57 controls were also assessed and compared, the result were significantly poor in cancer patients when compared to controls. In addition, there was significant improvement after therapy in patients with lymphomas and miscellaneous tumors. Pain and self-care were found to be maximally affected domains (Batra, et al, 2014).

A study was conducted to assess the overall QOL and specific functioning subscales of Nepalese children with leukemia, by using PedsQL 4.0 scale and to identify the determinants affecting QOL for 43 children with leukemia and their parents in Memorial Cancer Hospital. This study showed that QOL of both the child's self-report and parent

proxy report scores were highest in social functioning and lowest in emotional functioning subscale. Moreover, interclass correlation coefficient between proxy reports and self-reports were highest in physical functioning and lowest in social functioning subscales (V.K., et al, 2017).

In Portugal, a study has been conducted to assess the intensity of the treatment in pediatric cancer and to compare HRQOL among children and adolescents with different levels of treatment intensity, by using Treatment Rating Scale 3.0 and DISABKIDS Chronic Generic Measure (DCGM-12) scale. The result showed statistically significant differences in HRQOL associated with the level of treatment intensity. The children and adolescents with level 2 treatment intensity had higher HRQOL when compared with children/adolescents with levels 3 and 4 (Santos, et al, 2014).

A study was conducted in Iran to determine related factors to QOL among children with cancer by using relevant factors with QOL in children with cancer, PedsQL, and PedQL Cancer Modules for 89 children with cancer and showed that QOL mean score was (62.96%) and HRQOL mean score was (63%). Moreover, socio-demographic and clinical factors showed significant differences between child's age, father's occupation, and time elapse between periods of chemotherapy (Rahimi, et al, 2014).

Batalha et al, (2015) conducted a study in Portugal to describe the HRQOL among children with cancer by using PedQL Cancer Modules for 75 children aged between 8 and 17 years, and showed that HRQOL mean score was (66.0%). Variables related to the child's age, gender, type of tumor, time elapsed since diagnosis and number of hospitalizations did not influence the differences on HRQOL.

2.4.2 Regional studies

A study survey was designed in Jordan to identify the links between self-esteem, fatigue and HRQOL for children and young people during and following treatment for cancer by using validated measures of the attributes. This study was conducted in private rooms on the ward and in the outpatient clinic of a major oncology hospital in Jordan in 2015. Seventy children aged 5–16 years were included, the result of this study was that the total QOL score was (65.79%), and children with a high level of fatigue experienced a lower QOL (Al-Gamal and long, 2016).

Fawzy et al, (2013) conducted a study to measures HRQOL in Egyptian children with cancer. Parents of 67 included patients aged 8 - 12 years, were asked to complete the parent proxy report of PedsQL™ 3.0 Cancer Module (Arabic version), as well as a separate sheet for socio-demographic data. The result showed that the total HRQOL was relatively low. Moreover, increased treatment intensity, long duration of hospital admission, higher frequency of hospital visits, female sex, younger age at diagnosis, and large family size were all associated with a poorer total HRQOL and its subscales among Egyptian pediatric cancer patients.

A study was conducted in Lebanon to evaluate the HRQOL, symptom prevalence and symptom management among a sample of pediatric oncology patients. This study used PedsQL Cancer Module and the Memorial Symptom Assessment Scale were administered in Arabic using face-to-face interviews to a convenience sample of 85 pediatric cancer patients (7-18 years), at a tertiary hospital in Lebanon. The result showed that the total cancer scale score was (72.75%), and mean age of the study group was 12.5 years with leukemia being the most common cancer (43.5%). The lowest scores on the PedsQL subscales were in nausea and worry, thus indicating more problems in these areas. In children (7-12 years), lack of appetite, pain, and nausea were mostly prevalent whereas

adolescents (13-18 years) experienced lack of energy, irritability, and pain. In both age groups, pain and nausea were the most frequently treated symptoms (Abu-Saad Huijer, et al, 2013).

Mourner and Abolfotouh, (2007) conducted a study to assess the HRQOL in terms of physical, emotional and social functioning, to identify some predictors of QOL and to describe the educational achievement and nutritional status among school children with cancer in Alexandria, using PedsQL scale and anthropometric measurements for 215 students with cancer. The results showed that the mean percent QOL score of the total sample was (62.68%). Poor QOL was more likely among students of younger age and about two thirds of the sample reported poor educational achievement. In addition, (25.1%) were underweight and (87.4%) were anemic.

2.4.3 National studies

Here in Palestine, there are no studies about the QOL for children with cancer, but there are studies on QOL for adults with cancer, as follows:

Thweib, (2011) conducted a study in Palestine to highlight the concept of QOL for Palestinian cancer patients through providing an understanding about influences of cancer and chemotherapy on QOL of cancer patient, using European Organization for Research and Treatment of Cancer questionnaire EORTC QLQ-C30 (version 3.0) for 70 Palestinian cancer patients were aged between 18 and 70 years. The results showed that (48.6%) were men and (51.4%) were women and (62.8%) were in stages III and IV of cancer. The score of QOL was (48.4) and the domains functional scales ranged from (45.9) to (57.6), which indicate poor function and QOL.

A study was conducted to assess QOL in patients with cancer in the GS by using the EORTC QLQ C-30 (version 3.0) assessment tool for 364 cancer patients were aged above

18 years. The result showed that the global QOL was less than half of the full score (49.9%). Emotional function had the lowest score (47.7%). The highest score was the cognitive (67.6%), followed by the social functioning score (59.5%). The most frequent symptoms were financial difficulties (64.7%), pain (60.1%), fatigue (59.9%) and insomnia (58.1 %) (Shamallakh and Imam, 2017).

Chapter (3) Methodology

This chapter addresses issues related to methodologies used to answer the research questions. The chapter commences with study design, study population, sample and sampling method, study setting, and period of the study and eligibility criteria of the selection of study participants. In addition, this chapter presents the construction of the questionnaire, ethical consideration and procedures, data collection and data analysis.

3.1 Study design

The design of this study is descriptive, analytical and cross-sectional design. The researcher chooses to implement this design because it is the best design to describe the QOL. This type of study is useful to gather information on important health-related aspects of participants' knowledge at one a specific point of time. It is quick, cheap, easy to conduct, and it enables the researcher to meet the study objectives in a short time (Sedgwick, 2014).

3.2 Study population

In this study, the target population was all children with cancer aged 7-18 years who have medical records registered in hospitals of Ministry of Health (RSPH and EGH) in GS. It was estimated about: (112) child in RSPH and (22) child in EGH, from the unit of statistics in RSPH, EGH, and PHIC in GS.

3.3 Study setting

This study has been conducted at two main hospitals (RSPH and EGH) in GS.

3.4 Study period

The study period was 11 months; from November 2017 to September 2018.

3.5 Sampling

The researcher considered the population as the sample of study, because the population size is relatively small. However, the target population of study was 134 children, there were 12 patients traveling outside GS, therefore; the accessible population 122 children.

3.6 Eligibility criteria

3.6.1 Inclusion criteria

- Children with cancer aged from 7 to 18 years.
- Start chemotherapy at least one month.
- Children are able to response to the questionnaire.

3.6.2 Exclusion criteria

- Children who have a communication impairment.

3.7 Study instruments

3.7.1 Pediatric Quality of Life Inventory (PedsQL 4.0 generic core scale): The PedsQL scale was used for this study to assess QOL. The PedsQL scale is interviewer-administrated QOL scoring system. (Annex 9)

3.7.1.1 Scoring the PedsQL generic core scale

The PedsQL Generic Core Scales are easy to score. The 23-item multidimensional PedsQL 4.0 Generic Core Scales encompass 4 scales: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items).

The participants evaluated how often a specific problem occurred in the past month, A 5-point Likert response scale is utilized across interviewer-administrated for ages 7–18 years (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher PedsQL 4.0 scores

indicate better QOL (Varni et al, 2002). The Arabic version was validated in our culture and showed high reliability with Cronbach's alpha coefficient of 0.86 (Massad, et al, 2011).

3.7.2 PedsQL 3.0 cancer module: The PedsQL cancer module scale was used for this study to assess HRQOL. The PedsQL cancer module scale is interviewer-administrated HRQOL scoring system. (Annex 11)

3.7.2.1 Scoring the PedsQL cancer module scale

The 27-item multidimensional PedsQL 3.0 Cancer Module Acute Version encompasses 8 scales: pain and hurt (2 items), nausea (5 items), procedural anxiety (3 items), treatment anxiety (3 items), worry (3 items), cognitive problems (5 items), perceived physical appearance (3 items), and communication (3 items). The format, instructions, Likert response scale, and scoring method are identical to the PedsQL 4.0 Generic Core Scales Acute Version, with higher scores indicating better HRQOL (Varni et al, 2001 and Varni et al, 2003). The Arabic version was used in the Egypt society and showed high reliability (Fawzy, et al, 2013), the researcher obtained approval for using the Arabic version from Mapi research Institute in Lyon, France. (Annex 8).

3.8 Pilot study

A pilot study on 16 children was done and included with the sample of this study to assess the adequacy of the data collection plan, to explorer whether respondents understand the questions in the same way, to reduce the problems which may rise during data collection, to identify all domains and components of instrument and to determine the particular time needed to fill the two questionnaires.

3.9 Ethical and administrative consideration

The ethical, administrative considerations and procedures are very important conditions in applying the research. All of the ethical procedures have to be followed perfectly without ignoring any of them.

- An academic approval has been obtained from the Al-Quds University to conduct the study.
- An official letter of approval was obtained from Helsinki Committee in GS (Annex 5).
- An official letter was obtained from MOH to conduct this study (Annex 6 and 7).
- Every participant was provided with an explanatory form about the study including the purpose of the study, confidentiality of information and some instructions.
- The researcher assured the participant that all finding of the study would be used to guide the services providers to improve QOL for children with cancer.

3.10 Data collection

- Data were collected through a face-to-face interview by researcher himself at RSPH and by trained research assistant at EGH with each participant, and in the presence of his/her parent, the average of time to fill the questionnaire was 15-20 minutes.
- All questionnaire forms were prepared, organized, and classified with serial numbers to confirm the availability of the needed information.
- The researcher gave the participant appropriate time to answer the questions and assist them to be open and honest in answering
- The researcher explained the purpose of the questionnaire to the participant and family before obtaining consent form, and during the interview, any unclear

information was simplified by the researcher to ensure that he obtained accurate and adequate answers.

- The researcher conducted the interviews in the department of oncology and the outpatient clinic for each hospital, The data were collected at an appropriate time of the morning.

3.11 Data analysis

- Statistical analysis had been done using the Statistical Package for Social Science (SPSS) program version 22.
- The result were expressed as Descriptive statistics such as frequencies, means and percentages which were used to show sample characteristics differences.
- Inferential statistic, independent sample t test, and One-way ANOVA, were used to find the relationship between QOL dimension and other independent variables.

3.12 Limitation of the study

- Lack of previous studies, espacially QOL among children with cancer in Palestine.
- Difficult in collection of data from children espacially sick or exhusted ones.
- Difficulies in finding patients becouse we have just 2 days in a week to meet patients in RSPH, and 2 day in EGH (time-consuming process).
- Long hour's cut-off electricity which delayed internet searching and typing of research paper.

Chapter (4) Result & Discussion of the study

4.1 Result of the study

This chapter illustrates the results of statistical analysis of the data, including descriptive analysis that presents the socio - demographic characteristics of the study sample and answers to the study questions. The researcher used simple statistics including frequencies, means and percentages, as well as independent sample t test, and One-way ANOVA.

4.1.1 Socio-Demographic characteristics of the study sample

4.1.1.1 Sample distribution according to the participants' gender, hospital, and age groups

Table 4.1: Sample distribution according to the participants' gender, hospital, and age groups

Variables		Number	Percentage (%)
Gender	Male	66	54.1
	Female	56	45.9
Hospital	RSPH	106	86.9
	EGH	16	13.1
Age groups	≤ 9 years	68	55.7
	10-13 years	40	32.8
	14-18 years	14	11.5
	Total	122	100.0

Table 4.1 showed the distribution of study participants according to their gender, hospital, and age groups. The table showed that (54.1%) of study participants are males and (45.9%) of them are females. The table also showed that the majority (86.9%) of the study

participants are receiving their care and treatment from RSPH, and the rest (13.1%) are receiving their care from EGH. Moreover, 68 (55.7%) of the study participants are ≤ 9 years, 40 (32.8%) are between 10 and 13 years old, while 14 (11.5%) are between 14 and 18 years old.

4.1.1.2 Sample distribution according to the participants' residence

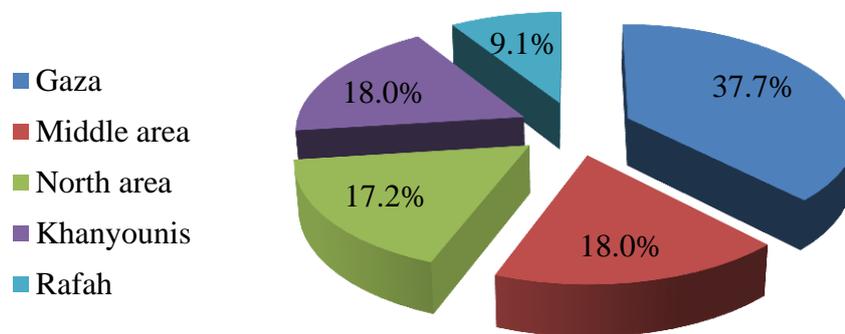


Figure 4.1: Sample distribution according to the participants' residence

Figure 4.1 showed that (37.7%) of the study participants are from Gaza governorate, (18.0%) are from middle area, (18.0%) are from Khanyounis, (17.2) are from North area, and (9.1%) are from Rafah.

4.1.1.3 Sample distribution according to the participants' families income

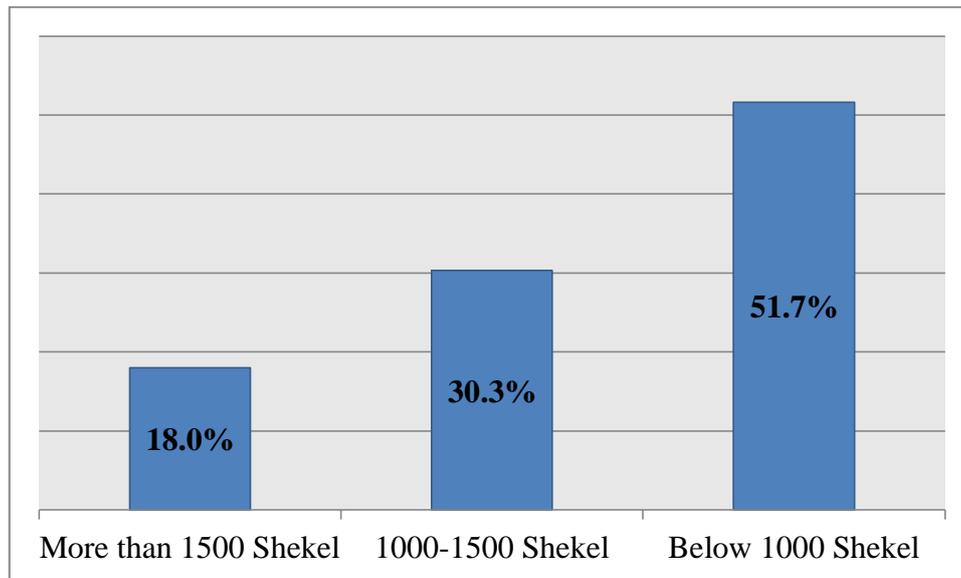


Figure 4.2: Sample distribution according to the participants' families' income

Figure 4.2 showed that (51.7%) of the study participants' families have income below 1000 Shekel, (30.3%) have income between 1000 and 1500 Shekel, while (18.0%) have income more than 1500 Shekel.

4.1.1.4 Sample distribution according to the participants' fathers level of education

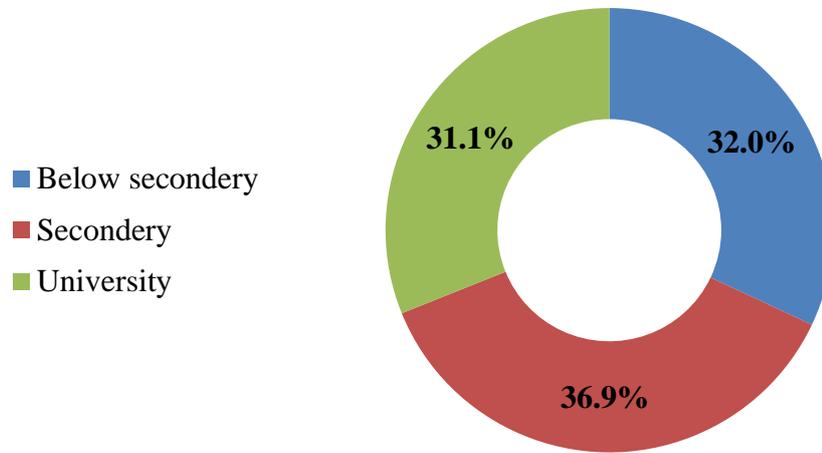


Figure 4.3: Sample distribution according to the participants' fathers level of education

Figure 4.3 showed that (36.9%) of the participants' fathers have secondary education, (32.0%) have below secondary education and (31.1%) of them have university degree.

4.1.1.5 Sample distribution according to the participants' mothers level of education

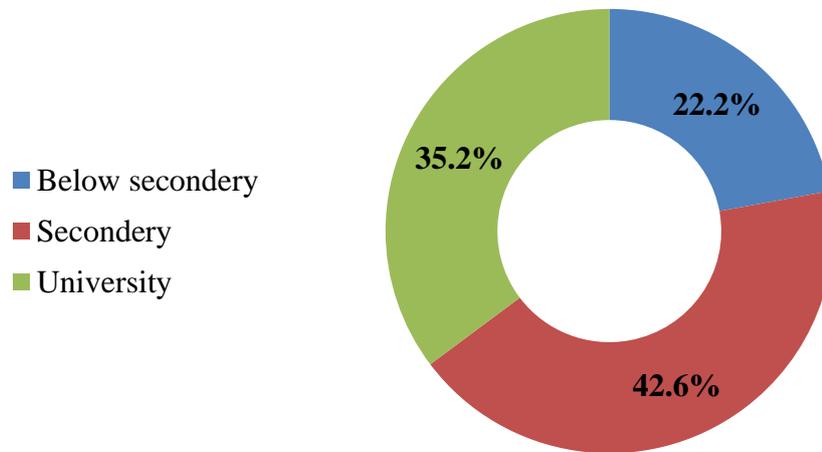


Figure 4.4: Sample distribution according to the participants' mothers level of education

Figure 4.4 showed that (42.6%) of the participants' mothers have secondary education, (35.2%) have university degree and (22.2%) have below secondary education.

4.1.1.6 Sample distribution according to the participants' fathers work, their mothers work, and number of family members

Table 4.2: Sample distribution according to the participants' fathers work, their mothers work, and number of family members

Variables		Number	Percentage (%)
Fathers work	Working	82	67.2
	Not	40	32.8
Mother work	Working	20	16.4
	Not	102	83.6
Number of family members	≤ 4 members	59	48.4
	5 – 7 members	46	37.7
	≥ 8 members	17	13.9
	Total	122	100.0

Table 4.2 showed that (67.2%) of the participants' fathers are working and (32.8%) are not working. It also shows that (83.6%) of the participants' mothers are not working and only (16.4%) of them are working. Regarding the number of family members at the participants' homes; (48.4%) of them are living with ≤ 4 members, (37.7%) are living with 5 – 7 members, while (13.9%) of them are living with ≥ 8 members.

4.1.2 Health profile variables of the study sample

4.1.2.1 Diagnosis years for the current disease and family history.

Table 4.3: Diagnosis years for the current disease and family history.

Variables		Number	Percentage (%)
Diagnosis years	< 1 year	31	25.4
	1– 2 years	25	20.5
	More than 2 years	66	54.1
Family history	Present	28	23.0
	Not	94	77.0
	Total	122	100.0

Table 4.3 showed the distribution of study participants according to their number of diagnosis years and family history of cancer. The table showed that 66 (54.1%) of the study participants were diagnosed with cancer since more than 2 years, 31 (25.4%) of them were diagnosed with cancer since below 1 years, while 25 (20.5%) were diagnosed with cancer since 1– 2 years. Additionally, the table showed that the majority (77.0%) of the study participants do not have family history of cancer, while (23.0%) of them do.

4.1.3 QOL among children with cancer in the GS

Table 4.4: Mean percentage of each QOL domain among children with cancer in the GS

No	Area	Mean %
Physical function		52.94
1	It is hard for me to walk more than a couple of streets (about 100 meters)	33.61
2	It is hard for me to run	54.71
3	It is hard for me to do sports activities or exercise	56.56
4	It is hard for me to lift heavy things	52.25
5	It is hard for me to have a bath or shower by myself	67.42
6	It is hard for me to do chores around the house	64.96
7	I have aches and pains	47.31
8	I feel tired	46.93
Emotional function		47.13
1	I feel afraid or scared	47.34
2	I feel sad	44.47
3	I feel angry	38.32
4	I have trouble sleeping	55.33
5	I worry about what will happen to me	50.20
Social function		60.98
1	I have trouble getting on with other children	58.81
2	Other children do not want to be my friend	65.57
3	Other children tease me	57.79
4	I cannot do things that other children my age can do	57.79
5	It is hard to keep up when I play with other children	57.99
School function		48.85
1	It is hard to pay attention in class	53.28
2	I forget things	54.10
3	I have trouble keeping up with my school work	52.66
4	I miss school because of not feeling well	47.34
5	I miss school to go to the doctor or hospital	36.89
Total mean % score		52.53

Table 4.4 showed the mean percentage of each QOL domain among children with cancer in the GS. The table showed that the highest QOL domain is social functioning which has a score of (60.98%) out of 100.0%, with the highest item is “Other children do not want to be my friend” and the lowest item is “It is hard to keep up when I play with other children”, followed by physical functioning domain which has a score of (52.94%) with

highest item is “It is hard for me to have a bath or shower by myself” and the lowest item is “It is hard for me to walk more than a couple of streets “. On the other hand, the QOL domain related to the school functioning has a score of (48.85%) with the highest item is “I forget things” and the lowest item is “I miss school to go to the doctor or hospital”, and the emotional functioning domain has a score of (47.13%) with highest item is “I have trouble sleeping” and the lowest item is “I feel angry”. The total mean percentage of the QOL is (52.53%).

4.1.4 HRQOL among children with cancer in the GS

Table 4.5: Mean percentage of HRQOL among children with cancer in the GS

No	Area	Mean %
Pain and Hurt		48.97
1	I ache or hurt in my joints and/or muscles	48.36
2	I hurt a lot	49.59
Nausea		62.37
1	I become sick to my stomach when I have medical treatments	54.10
2	Food does not taste very good to me	64.96
3	I become sick to my stomach when I think about medical treatments	60.04
4	I feel too sick to my stomach to eat	64.55
5	Some foods and smells make me sick to my stomach	68.24
Procedural Anxiety		24.38
1	Needle sticks (i.e. injections, blood tests, IV's) hurt	26.23
2	I get scared when I have to have blood tests	23.98
3	I get scared about having needle sticks (i.e. injections, blood tests, IV's)	22.95
Treatment Anxiety		38.18
1	I get scared when I am waiting to see the doctor	38.32
2	I get scared when I have to go to the doctor	39.75
3	I get scared when I have to go to the hospital	36.48
Worry		42.14
1	I worry about side effects from medical treatments	44.88
2	I worry about whether or not my medical treatments are working	42.83

No	Area	Mean %
3	I worry that my cancer will come back or relapse	38.73
Cognitive Problems		53.68
1	It is hard for me to figure out what to do when something bothers me	56.35
2	I have trouble solving math problems	51.23
3	I have trouble writing school papers or reports	51.64
4	It is hard for me to pay attention to things	53.89
5	It is hard for me to remember what I read	55.33
Perceived Physical Appearance		55.66
1	I feel I am not good looking	64.75
2	I don't like other people to see my scars	51.02
3	I am embarrassed when others see my body	51.23
Communication		50.54
1	It is hard for me to tell the doctors and nurses how I feel	53.48
2	It is hard for me to ask the doctors and nurses questions	56.15
3	It is hard for me to explain my illness to other people	42.01
Total mean % score		48.55

Table 4.5 showed the mean percentage of each HRQOL domain among children with cancer in the GS. The table showed that the highest HRQOL domain is “Nausea” which has a score of (62.37%) out of 100.0%, followed by “Perceived physical appearance” domain which has a score of (55.66%). On the other hand, the lowest HRQOL domain score is “Procedural anxiety“ which has a score of (24.38%). The total mean percentage of the HRQOL is (48.55%).

4.1.5 Differences in the QOL and HRQOL between male and female children in the GS

Table 4.6: Differences in the QOL and HRQOL between male and female Children in the GS

Variable	Mean (SD)		<i>t</i> statistics (df)	<i>p</i> value *
	Males	Females		
Quality of Life	52.56 (20.70)	52.50 (17.98)	0.018 (120)	0.985
Health- Related Quality of Life	49.74 (21.24)	47.15 (19.54)	0.696 (120)	0.488

*Independent sample *t* test

Table 4.6 showed that there is no statistically significant difference in the QOL between male and female children in the GS ($p > 0.05$). Also, there is no statistically significant difference in the HRQOL between male and female children in the GS ($p > 0.05$).

4.1.6 Differences in the QOL and HRQOL between children who receive their care in RSPH and in EGH

Table 4.7: Differences in the QOL and HRQOL of Life between children who receive their care in RSPH and in EGH

Variable	Mean (SD)		<i>t</i> statistics (df)	<i>p</i> value *
	RSPH	EGH		
Quality of Life	52.05 (20.13)	55.77 (13.83)	-0.713 (120)	0.477
Health- Related Quality of Life	48.17 (21.06)	51.09 (16.00)	-0.532 (120)	0.596

*Independent sample *t* test

Table 4.7 showed that there is no statistically significant difference in the QOL and HRQOL between the children who are receiving their treatment in RSPH and those are receiving their treatment in the EGH ($p>0.05$).

4.1.7 Differences in QOL and HRQOL between their different age groups of the children

Table 4.8: Differences in the QOL and HRQOL between their different age groups of the children

Variable	N	Mean (SD)	F (df)	<i>P</i> value*
Quality of Life				
≤ 9 years	68	52.62 (19.95)	1.033 (2, 119)	0.359
10 – 13 years	40	50.19 (19.36)		
14 – 18 years	14	58.85 (16.58)		
Health- Related Quality of Life				
≤ 9 years	68	48.88 (21.80)	0.326 (2, 119)	0.722
10 – 13 years	40	46.85 (19.20)		
14 – 18 years	14	51.85 (17.65)		

*One way ANOVA

Table 4.8 showed that there is no statistically significant difference in the QOL between different age groups of the children ($p>0.05$). Also, there is no statistically significant difference in HRQOL between different age groups of the children ($p>0.05$).

4.1.8 Differences in the QOL and HRQOL between their different areas of residence

Table 4.9: Differences in the QOL and HRQOL between their different areas of residence

Variable	N	Mean (SD)	F (df)	P value*
Quality of Life				
Gaza Governorate	46	55.38 (19.54)	0.708 (4, 117)	0.855
North area	21	47.04 (14.18)		
Middle area	22	53.60 (17.73)		
Khanyounis Governorate	22	51.23 (26.74)		
Rafah Governorate	11	51.58 (13.74)		
Health- Related Quality of Life				
Gaza Governorate	46	50.84 (20.91)	0.661 (4, 117)	0.620
North area	21	44.04 (17.16)		
Middle area	22	45.49 (17.89)		
Khanyounis Governorate	22	51.76 (26.93)		
Rafah Governorate	11	47.30 (13.84)		

*One way ANOVA

Table 4.9 showed that there is no statistically significant difference in the QOL among children between their different areas of residence ($p>0.05$). Also, there is no statistically significant difference in the HRQOL among children between their different areas of residence ($p>0.05$).

4.1.9 Differences in the QOL and HRQOL between their different families' income

Table 4.10: Differences in the QOL and HRQOL between their different families' income

Variable	N	Mean (SD)	F (df)	P value*
Quality of Life				
Below 1000 Shekel	63	47.55 (17.85)	4.693 (2, 119)	0.011*
1000 – 1500 Shekel	37	58.84 (20.18)		
More than 1500 Shekel	22	56.22 (19.37)		
Health- Related Quality of Life				
Below 1000 Shekel	63	43.95 (19.62)	4.423 (2, 119)	0.014*
1000 – 1500 Shekel	37	56.20 (19.57)		
More than 1500 Shekel	22	48.86 (21.14)		

*One way ANOVA

Table 4.10 showed that there is statistically significant difference in the QOL among children between their different families' income ($p < 0.05$). Post hoc analysis was done using Scheffe test and showed that the difference is between those who have family income below 1000 Shekel and 1000 – 1500 Shekel in favor of those who have family income 1000 – 1500 Shekel.

Also, there is statistically significant difference in the HRQOL among children between their different families' income ($p < 0.05$). Post hoc analysis was done using Scheffe test and showed that the difference is between those who have family income below 1000 Shekel and 1000 – 1500 Shekel in favor of those who have family income 1000 – 1500 Shekel.

4.1.10 Differences in the QOL and HRQOL between their different fathers' education level

Table 4.11: Differences in the QOL and HRQOL between their different fathers' education level

Variable	N	Mean (SD)	F (df)	P value*
Quality of Life				
Below secondary	39	53.03 (18.64)	0.519 (2, 119)	0.597
Secondary	45	50.33 (18.56)		
University	38	54.63 (21.35)		
Health- Related Quality of Life				
Below secondary	39	49.31 (22.18)	0.645 (2, 119)	0.526
Secondary	45	45.92 (16.89)		
University	38	50.90 (22.52)		

*One way ANOVA

Table 4.11 showed that there is no statistically significant difference in the QOL among children between their different fathers' educational level ($p > 0.05$). Also, there is no statistically significant difference in the HRQOL among children between their different fathers' educational level ($p > 0.05$).

4.1.11 Differences in the QOL and HRQOL between their different mothers' education level

Table 4.12: Differences in QOL and HRQOL between their different mothers' education level

Variable	N	Mean (SD)	F (df)	P value*
Quality of Life				
Below secondary	27	56.32 (19.39)	2.417 (2, 119)	0.094
Secondary	52	48.11 (19.71)		
University	43	55.51 (18.43)		
Health- Related Quality of Life				
Below secondary	27	50.37 (24.03)	1.301 (2, 119)	0.276
Secondary	52	45.13 (19.26)		
University	43	51.55 (19.23)		

*One way ANOVA

Table 4.12 showed that there is no statistically significant difference in the QOL among children between their different mothers' educational level ($p > 0.05$). Also, there is no statistically significant difference in the HRQOL among children between their different mothers' educational level ($p > 0.05$).

4.1.12 Differences in the QOL and HRQOL between different number of family members

Table 4.13: Differences in the QOL and HRQOL between different number of family members

Variable	N	Mean (SD)	F (df)	P value*
Quality of Life				
≤ 4 members	59	57.64 (20.01)	4.816 (2, 119)	0.010*
5 – 7 members	46	49.36 (16.86)		
≥ 8 members	17	43.41 (19.69)		
Health- Related Quality of Life				
≤ 4 members	59	51.25 (21.87)	1.486 (2, 119)	0.231
5 – 7 members	46	47.56 (18.06)		
≥ 8 members	17	41.88 (0.73)		

*One way ANOVA

Table 4.13 showed that there is statistically significant difference in the QOL among children between their different number of family members ($p < 0.05$). Post hoc analysis was done using Scheffe test and showed that the difference is between those who have family members \leq four and those who have \geq 8 members in favor of those who have family members \leq 4 members. On the other hand, there is no statistically significant difference in the HRQOL among children between their different number of family members ($p > 0.05$).

4.1.13 Differences in the QOL and HRQOL between father's working status

Table 4.14: Differences in the QOL and HRQOL between father's working status

Variable	Mean (SD)		<i>t</i> statistics (df)	<i>p</i> value *
	Working	Not		
Quality of Life	54.12 (19.07)	49.29 (19.96)	1.293 (120)	0.199
Health- Related Quality of Life	50.93 (19.78)	43.68 (21.15)	1.859 (120)	0.065

*Independent sample *t* test

Table 4.14 showed that there is no statistically significant difference in the QOL among children between those who have working father and who do not ($p > 0.05$). Also, there is no statistically significant difference in the HRQOL among children between those who have working father and who do not ($p > 0.05$).

4.1.14 Differences in the QOL and HRQOL between mother's working status

Table 4.15: Differences in the QOL and HRQOL between mother's working status

Variable	Mean (SD)		<i>t</i> statistics (df)	<i>p</i> value *
	Working	Not		
Quality of Life	48.64 (12.85)	53.30 (20.42)	-1.327 (40.61)	0.192
Health- Related Quality of Life	42.91 (14.37)	49.66 (21.31)	-1.755 (37.59)	0.087

*Independent sample *t* test

Table 4.15 showed that there is no statistically significant difference in the QOL among children between those who have working mother and who do not ($p > 0.05$). Also, there is no statistically significant difference in the HRQOL among children between those who have working mother and who do not ($p > 0.05$).

4.1.15 Differences in the QOL and HRQOL between their different diagnosis years of the disease

Table 4.16: Differences in the QOL and HRQOL between their different diagnosis years of the disease

Variable	N	Mean (SD)	F (df)	P value*
Quality of Life				
> 1 year	31	51.85 (20.97)	0.389 (2, 119)	0.678
1– 2 years	25	55.60 (16.95)		
More than 2 years	66	51.69 (19.71)		
Health- Related Quality of Life				
> 1 year	31	46.62 (19.31)	0.190 (2, 119)	0.827
1– 2 years	25	49.62 (19.64)		
More than 2 years	66	49.06 (21.46)		

*One way ANOVA

Table 4.16 showed that there is no statistically significant difference in the QOL among children between their different years of cancer diagnosis ($p>0.05$). Also, there is no statistically significant difference in the HRQOL among children between their different diagnosis years of cancer diagnosis ($p>0.05$).

4.1.16 Differences in the QOL and HRQOL between those who have family history of cancer and who do not

Table 4.17: Differences in the QOL and HRQOL between those who have family history of cancer and who do not

Variable	Mean (SD) of History		<i>t</i> statistics (df)	<i>p</i> value *
	Present	Absent		
Quality of Life	50.65 (19.36)	53.09 (19.50)	-0.582 (120)	0.562
Health- Related Quality of Life	45.63 (19.90)	49.42 (20.62)	-0.861 (120)	0.391

*Independent sample *t* test

Table 4.17 showed that there is no statistically significant difference in the QOL among children between those who have family history of cancer and who do not ($p > 0.05$). Also, there is no statistically significant difference in the HRQOL among children between those who have family history of disease and who do not ($p > 0.05$).

4.2 Discussion of the study

The main aim of this study is to assess the QOL among children with cancer in GS. In this section, the previously mentioned results are discussed in details within the current status of GS and the nature of study conducted, also these results are discussed within the scope of previous studies.

4.2.1 Socio- economic and demographic characteristics

In this study, the result showed that (54.1%) of the study participants are males, while (45.9%) of them are females. It is consistent with Elnuweiry, (2015) the result conducted that male was (55.5%) while female was (44.5%), this concluded that males are more affected by cancer. The results were also agree with Vlachioti et al, (2016) who conducted

study to assess the QOL of adolescents with cancer and survivors of childhood cancer, which found that (57.1%) of the study participants are males, while (42.9%) of them are females. The results were furthermore supported by Fawzy et al, (2013) who conducted a study to measure QOL in Egyptian children with cancer, the results showed that the ratio of males to females was 1.8:1 among study patients.

Moreover, this study showed that there is no statistically significant difference in the QOL and HRQOL between male and female children with cancer in the GS, which is inconsistent with Al-Gamal and long, (2016) designed a study in Jordan to identify the links between self-esteem, fatigue and HRQOL for children and young people during and following treatment for cancer, that indicated that boys experienced better total QOL and better physical functioning than girls, and consistent with Batalha et al, (2015) conducted a study to describe HRQOL among children with cancer, and showed that there is no statistically significant difference in the QOL and gender.

The results of this study showed that (55.7%) of the study participants are ≤ 9 years, 40 (32.8%) are between 10 and 13 years old, while (11.5%) are between 14 and 18 years old. The highest percentage was observed among child aged ≤ 9 years, while the lowest was observed among child aged 14- 18 years, and the results showed that there is no statistically significant difference in the QOL and HRQOL between different age groups, This results are consistent with Al Gamal and long, (2016) the results of which showed no statistically significant differences between age of the child and total scale QOL, and consistent with Batalha et al, (2015) that indicated no statistically significant differences between the QOL and age.

Here, the researcher explains that the percentage of cancer among children with cancer above 13 years is low compared with younger child, taking into account the nature of the disease and its complications that led to death with increasing age.

Moreover, the findings of this study revealed that (86.9%) of children with cancer were treated at RSPH, it is the first main hospital that provides children cancer care in GS. This resulted in inclusion of the highest number of children from this hospital in the study. The EGH is the second main hospital, which takes care of (13.1%) of children cancer. It provide services to adolescent from Khanyounis and Rafah Governorate. Furthermore, the study showed that there is no statistically significant difference in the QOL and HRQOL between children who are receiving their treatment in RSPH and in EGH

The study showed that children cancer from Gaza Governorate constituted the highest number (37.7%), while Rafah Governorate constituted the lowest number (9.1%). This result consisted with Elnuweiry, (2015) that Gaza Governorate had the highest number of participant (40.4%) and the lowest number of cases was in Rafah Governorate (5.5%). Moreover, the result of this study showed that there is no statistically significant difference in the QOL and HRQOL among children between their different areas of residence.

The researcher explains that children cancer in Gaza City represent the highest number compared to other cities in view of the higher population density. As the incidence of children cancer in Gaza Governorate was higher, this might have caused most of children at RSPH more than at EGH.

The results showed that the highest percentage was found in participants' families' income of below 1000 Shekel (51.7%), while the lowest percentage was found in income was more than 1500 Shekel. This results are consistent with Elnuweiry, (2015) that found that highest percentage (46.6%) of cases have a monthly income below1000 shekel. The results

of this study showed that there is statistically significant difference in the QOL and HRQOL among children between their different families' income. This results disagree with Eilertsen et al, (2011) that explored subjective and proxy reported QOL in children and adolescents surviving cancer three years after diagnosis compared with healthy controls, and showed that there was no statistically significant differences of children' cancer QOL in view of monthly income. It is also inconsistent with Al Gamal and long, (2016) that showed no statistically significant differences between family income and QOL for children with cancer.

The researcher believed that the G.S population is depending on the very low economic status imposed by the siege. This makes it difficult for families to provide a basic health requirement for suffering children, thus, suppressing their QOL further.

Regarding parents education, this study showed that children whose mothers have secondary education had the highest level among study population (42.6%), while (22.2%) of mothers have below secondary education. Moreover, children whose fathers have secondary education constituted the highest level among the study population (36.9%), while (31.1%) of them have university degree. These results agreed with Elnuweiry, (2015) that children' mother have secondary education was the highest level among study population (44.5%), and disagreed that children' father have below secondary education was the highest level among study population (35.6%). Addition, the study results showed that there is no statistically significant difference in the QOL and HRQOL among children between their parents' educational level, these results supported by Eilertsen et al, (2011) there was no statistically significant differences between children' cancer QOL in view of parents' educational level.

Furthermore, the study results showed that (16.4%) of the participants' mothers are working, while (67.2%) of the participants' fathers are working. These results are consistent with Elnuweiry, (2015) showed that child' mothers who work were (8.9%), while child father who work (87.7%). In addition, this study showed that there is no statistically significant difference in the QOL among children between those who have working mother and who do not. Also, there is no statistically significant difference in the HRQOL among children between those who have working mother and who do not. Moreover, the result showed that there is no statistically significant difference in the QOL among children between those who have working father and who do not. Also, there is no statistically significant difference in the HRQOL among children between those who have working father and who do not. These results are consistent with Chirivella et al, (2009) which assessed the HRQOL of children with cancer in India and showed that there is no statistically significant difference in the HRQOL among children' parent occupation. However, they disagree with Rahimi et al, (2014) which showed that there is statistically significant difference in the HRQOL among children who have working father.

The researcher believed that the siege, low economic situation in the GS and early marriage, forced many Palestinian citizens to leave education at an early stage, and increased rate of unemployment in GS.

The results showed that there is statistically significant difference in the QOL among children between their different number of family members, and there is no statistically significant difference in the HRQOL among children between their different number of family members. These results disagree with Vlachiotti et al, (2016) that showed no statistically significant difference in the QOL among children between their different number of family members.

The researcher believes that with a lesser number of family members, parents and caregivers can pay more attention to each individual child, and especially to a child with cancer that is in need for constant care and extra effort to improve his/her QOL.

4.2.2 Health profile variables

This study showed that (54.1%) of the study participants were diagnosed since more than 2 years, 31 (25.4%) of them were diagnosed since below 1 years, while 25 (20.5%) were diagnosed since 1– 2 years, and there is no statistically significant difference in the QOL and HRQOL among children between their different diagnosis years of disease, these results are consistent with Vlachioti et al, (2016) that conducted a study to evaluate the QOL of children and adolescents with any type of cancer and showed that the QOL of children and adolescents does not have statistically significant difference change during diagnosis years of the disease, and inconsistent with Fakhry et al, (2013) that conducted a study to measures HRQOL in Egyptian children with cancer and showed that newly diagnosed childhood cancer patients have been shown to have poorer scores on all domains of HRQOL. Another study disagree with these results that was conducted by Rodgers et al, (2015) and showed that overall moderate improvement in HRQOL scores between one and six months post Hematopoietic Stem Cell Transplant Recovery.

The researcher explains that children with cancer has been facing problems; such as nature of the disease, shortage of medical supply and drugs, parents' lack of awareness about the impending death of their children, the Israeli's siege that prevents patients from receiving care and consequence of the disease all make the years of cancer suffering for children with cancer.

This study also showed that (77.0%) of the study participants do not have family history of cancer, while (23.0%) of them have family history of cancer, and there is no statistically

significant difference in the QOL and HRQOL among children between those who have family history of disease and who do not.

4.2.3 QOL and HRQOL among children with cancer

This study showed that the total mean percentage of the QOL was (52.53%), the social function domain got the highest score (60.98%). Moreover, the physical function domain (52.94%), the school function domain (48.85%), and the lowest domain was emotional function domain with equaled (47.13). The total mean percentage of the HRQOL was (48.55%), the nausea domain got the highest score (62.37%). Furthermore, the perceived physical appearance domain was (55.66%), the cognitive problems domain (53.68%), the communication domain (50.54%), the pain and hurt domain (48.97%), the worry domain (42.14%), the treatment anxiety domain (38.18%), and the lowest domain were procedural anxiety with equaled (24.38%).

Al-Gamal and Long, (2016) showed that the total QOL score was (65.79%). The social domain got the highest score and the school domain score (48.25%), these results do not commensurate with the current study.

Fawzy et al, (2013) conducted that the total HRQOL relatively low, subscales with least scores were for worry (44.11%), perceived physical appearance (50.6%), and procedural anxiety (55.34%). On the other hand, the best score was (75.98%) for communication, followed by (72.63%) for cognitive problems, these results commensurate with the current study that the total HRQOL participants have a low level , and does not commensurate in HRQOL domains score.

Moreover, Abu-Saad Huijer et al, (2013) evaluated the HRQOL, symptom prevalence and management and the quality of palliative care provided to Lebanese children with cancer from their parents' perspectives, and showed that the total cancer scale score was (72.75%) indicating acceptable HRQOL. In addition, the highest scores among the subscales were

communication and cognitive problems, the lowest scores denoting more problems as viewed by the parents were found in nausea, treatment anxiety and worry. This result does not commensurate with the current study.

Mounir and Abolfotouh, (2007) conducted a study to assess the QOL among school children with cancer in Alexandria, showed that the mean QOL score of the total sample was (62.68%). This was significantly higher for males than for females. The physical domain got the highest score, then the emotional domain score (34.4%), and the social domain (26%). This is inconsistent with the study.

In the study conducted by Rahimi et al, (2014) to determine related factors to QOL among children with cancer and found that the total mean percentage of QOL was (62.96%) and HRQOL mean percentage was (63.0%). These results are inconsistent with this study that QOL score was (52.53%), and HRQOL score was (48.55%) as a low level.

Moreover, Nazari et al, (2017) conducted a study to compare the QOL, anxiety and depression in children with cancer and showed that QOL among children with cancer participating in the study score was low, and this commensurate with this study. Moreover, Rosenberg et al, (2016) conducted a study to describe QOL among children with cancer and its relationship to symptom distress and showed that the total mean percentage of QOL was low level. This consistent with this study.

Yağc-Küpelı et al, (2012) conducted a study to evaluate the HRQOL and the effect of associated factors and showed that the total mean percentage of HRQOL was (77.8%), this results disagree with our results. Pan et al (2017) conducted a study to assess differences in QOL, distress behavior, and fatigue among children and adolescents with cancer and showed that the total mean percentage of QOL was (80.37%). This results does not commensurate with our study.

The researcher explains that cancer is considered an exhausting, and chronic nature of the disease itself in terms of frequent hospital visits, drug availability, side effects of drug and disease complication and consequence of the disease. In addition, parents' lack of awareness about the impending death of their children, along with Israeli's occupation siege that prevents patients from receiving care, all of this negatively impacts on QOL and HRQOL for children with cancer in GS.

Chapter (5) Conclusion and Recommendations

This chapter provide the main conclusion and recommendations for the decision makers to focus on improving and increasing the QOL for children with cancer.

5.1 Conclusion

Cancer is considered one of the major health problems worldwide, including Palestine. Because of QOL among children cancer are relatively reduced, improvement of life's dimensions is important for achieving better coping with disease. Early detection and treatment of cancer among children should be enhanced to prevent progression of the disease and decrease in QOL. This study determines what is important for understanding how cancer disease affects in QOL of children.

This study has used descriptive, analytical and cross-sectional design to provide a comprehensive assessment of the QOL among children with cancer in GS. It also showed how cancer affects in HRQOL among children with cancer in GS. Moreover, it provides powerful and multidimensional concepts about QOL and HRQOL among children cancer.

This study has been conducted to assess QOL among children with cancer who live in GS. The study discovers the four PedsQL core domains and seven PedsQL cancer module domains. It also explorer effects of demographic, socioeconomic, and health profile variable in QOL for children with cancer.

The result showed that the children with cancer in GS had low level of QOL (52.53%) and HRQOL (48.55%). The results showed that there is statistically significant difference in the QOL and HRQOL among children between their different families' income. Moreover, the result showed that there is statistically significant difference in the QOL among children between their different number of family members. On the other hand, there is no

statistically significant difference in the HRQOL among children between their different number of family member.

5.2 Recommendation

This study has provided useful information about QOL of children with cancer in GS. The results might help in developing deep understanding of the issues that may influence subjects' overall health as their QOL. Furthermore, due to significant decrease in QOL domains among children with cancer in GS. I recommended to emphasize on increasing the efforts to avoid negative impacts on QOL as following:

- Adoption programs that can enhance the level of QOL.
- Psychosocial support should be schedule for children and their families.
- Providing psycho-oncology services in MOH together with medical treatment.
- Encourage of communication skills for healthcare givers.
- Guiding the society on how children with cancer should be treated through improve the awareness and educational campaign.
- Enhancing pain management and anxiety reduction measurements.
- Improving early detection of cancer and establish measurements for that, this will increase the possibility of surviving and limits the deterioration of children' QOL.
- Work collaboratively with local, regional, and national organizations related to children cancer advocacy, awareness, prevention, research, treatment, and support.
- Develop a website of information on current cancer research and studies conducted in Palestine instead of awareness public about children cancer.

5.3 Recommendation for further research

- The effect of psychological program among children with cancer.
- QOL among caregivers in oncology department at the hospitals of MOH.

References

- Abed, Y., El Saka, B., Hamdan, Kh., Abo Saman, Kh., Yaghi, H. (2012): "Cancer incidence in the Gaza Strip, Palestine (2000-2010)". Cancer Registry: MOH.
- Abu Amar, W., Abed. Y.(2012): Cancer Prevention and Control. Evaluation of the Strategy in Gaza Governorates. Gaza: LapLambet.
- Abu-Saad Huijer, H., Sagherian, K., Tamim, H. (2013): Quality of life and symptom prevalence as reported by children with cancer in Lebanon. *European Journal of Oncology Nursing*, 17(6), pp.704-710.
- Al-Gamal, E., Long, T. (2016): Health-related quality of life and its association with self-esteem and fatigue among children diagnosed with cancer. *Journal of Clinical Nursing*, 25(21-22), pp.3391-3399.
- Aspinall, P. A., Hill, A. R., Dhillon, B., Armbrecht, A. M., Nelson, P., Lumsden, C., et al (2007): Quality of life and relative importance: A comparison of time trade-off and conjoint analysis methods in patients with age-related macular degeneration. *British Journal of Ophthalmology*, 91(6), pp.766-772.
- Avoine-Blondin, J., Parent, V., Lahaye, M., Humbert, N., Duval, M., & Sultan, S. (2017): Identifying domains of quality of life in children with cancer undergoing palliative care: A qualitative study with professionals. *Palliative and Supportive Care*, 15(05), pp.565-574.
- Ayoub, A., Hijjazi, K. (2013): Quality of life in dialysis patients from the United Arab Emirates. *Journal of Family and Community Medicine*, 20(2), p.106.

- Ballantine, K. (2017): The incidence of childhood cancer in New Zealand 2010-2014: A report from the New Zealand Children's Cancer Registry. Auckland. National Child Cancer Network.
- Barcaccia, B., Esposito, G., Matarese, M., Bertolaso, M., Elvira, M., & Marinis, M. G. (2013): Defining Quality of Life: A wild Goose Chase?. *Europe s Journal of Psychology*,9(1): pp. 185-203
- Batalha, L. M., Fernandes, A. M., Campos, C. D. (2015): Quality of life among children with cancer: agreement between child and parent reports. *Esc Anna Nery*, 9(2): pp. 292-296
- Batra, P., Kumar, B., Gomber, S., Bhatia, M. (2014): Assessment of quality of life during treatment of pediatric oncology patients. *Indian Journal of Public Health*, 58(3), p. 168.
- Center of Disease Control and Prevention-CDC (2014): Cancer Prevention and Control, a Global Concern. 1600 Clifton Rd. Atlanta, USA.
- Centers of Disease Control and Prevention (2016): Health Related Quality of Life Concepts. (<http://www.cdc.gov/hrqol/concept.htm>, 11,7, 2018).
- Chaturvedi, S. K., Muliya, K. P. (2016): The Meaning in Quality of Life. *Journal of Psychosocial Rehabilitation and Mental Health*, 3(2), pp. 47-49
- Chirivella, S., Rajappa, S., Sinha, S., Eden, T., Barr, R. D. (2009): Health-related quality of life among children with cancer in Hyderabad, India. *The Indian Journal of Pediatrics*, 76(12), pp. 1231-1235.

- Chung, O., Li, H., Chiu, S., Lopez, V. (2012): Predisposing Factors to the Quality of Life of Childhood Cancer Survivors, *Journal of Pediatric Oncology Nursing*, 29(4), pp. 211-2200.
- Costanza, R., Fisher, B., Ali, S., Beer, C., Bond, L., Boumans, L., et al (2008): An Integrative Approach to Quality of Life Measurement, Research, and Policy. SAPIENS.
- Davidoff, A. (2010): *Pediatric Oncology. Semin Pediatr Surg*, 19(3): pp. 225–233.
- Devance, C. (2010): Living After Diagnosis Median Cancer Survival Time, *Macmillan Cancer Support*. 35(4), pp. 231-245.
- Dommett, R. M., Redaniel, M. T., Stevens, M. C., Hamilton, W., & Martin, R. M. (2012): Features of childhood cancer in primary care: A population-based nested case–control study. *British Journal of Cancer*, 106(5), pp. 982-987.
- Eilertsen, M. B., Rannestad, T., Indredavik, M. S., & Vik, T. (2011): Psychosocial health in children and adolescents surviving cancer, *Scandinavian Journal of Caring Sciences*, 25(4), pp.725-734.
- Elnuweiry, H. (2015): Risk Factors for Pediatric Cancer in the Gaza Strip, Case-Control Study. Al Quds University, Jerusalem – Palestine.
- Fakhry, H., Goldenberg, M., Sayer, G., Aye, S. S., Bagot, K., Pi, S., et al (2013): Health-Related Quality of Life in Childhood Cancer. *Journal of Developmental & Behavioral Pediatrics*, 34(6): pp. 419–440.
- Faris, G., Mouhamed, M., Al Jerf, F., Khder, N., Alnakry, E., Salamon, M., et al (2016): Rapid Assessment of Cancer Management Care in Syria, December- 2016.

Fawzy, M., Saleh, M., El-Wakil, M., Monir, Z., Eltahlawy, E. (2013): Quality of Life in Egyptian Children with Cancer. *Journal of Cancer Therapy*, 04(07), pp.1256-1261.

Foundation Health Measures (2010): Quality-of-Life-and-Well-Being

(<https://www.healthypeople.gov/2020/about/foundation-health-measures/Health-Related-Quality-of-Life-and-Well-Being>, 2,09, 2018).

Fryback, D.G. (2010): Measuring Health-Related Quality of Life. Workshop on Advancing Social Science Theory the Importance of Common Metrics. The National Academies, Division of Behavioral and Social Sciences and Education Washington, DC, USA: Springer

Haddou, B., El Rhazi, K., Ouasmani, F., Nejari, C., Bekkali, R., Montazeri, A., et al (2016): Quality of life in Arab women with breast cancer: a review of the literature. *Health Qual Life Outcomes*. 2016;14 (64): pp. 016–046

Hays, R., Reeve, B. (2010): Measurement and Modeling of Health-Related Quality of Life. *International Encyclopedia of Public Health*, pp. 241-252.

International Association of Cancer Registries (2015): International Childhood Cancer Day. Geneva, Switzerland.

International Society for Quality of Life Research- ISOQOL (2015): What is health-related quality of life research? (<http://www.isoqol.org/about-isoqol/what-is-health-related-quality-of-life-research>,3.6. 2018)

Lavdaniti, M., Tsitsis, N. (2015): Definitions and conceptual models of quality of life in cancer patients, *Health Science Journal*, 9(26), pp. 1-5.

- Massad, S. G., Nieto, F. J., Palta, M., Smith, M., Clark, R., Thabet, A. (2011): Health-related quality of life of Palestinian preschoolers in the Gaza Strip: A cross-sectional study. *BMC Public Health*, 11(1).
- Ministry of Health-MOH (2017a): Health annual report. Gaza, Palestine: Ministry of Health.
- Ministry of Health - MOH (2017b): Health annual report, Palestine. General Directorate of Health Policies and Planning. PHIS, MOH, Ramallah
- Ministry of Health (2013): Hospital annual report-Gaza, Palestine.
- Ministry of Health (2016): Health annual report-Ramallah, Palestine.
- Mounir, G., Abolfotouh, M. (2007): Assessment of health related quality of life among school children with cancer in Alexandria. *The Journal of the Egyptian Public Health Association*, 82(3-4): pp. 219-238.
- National Cancer Institute (2015): What Is Cancer?.
(<https://www.cancer.gov/about-cancer/understanding/what-is-cancer,11.11.2017>).
- National Cancer Institute (2017): Types of Cancer Treatment.
(<https://www.cancer.gov/about-cancer/treatment/types,8,07,2018>).
- National Cancer Registry Ireland (2017): Childhood cancer. *Cancer Trends* No 32. Cork.
- Nazari, B., Bakhshi , S., Kaboudi , M., Dehghan , F., Ziapour , A., Montazeri , N.(2017): A Comparison of Quality of Life, Anxiety and Depression in Children with Cancer and Healthy Children, Kermanshah-Iran. *Int J Pediatric*, 5(7): pp. 5305-14.

- Nunes, M., Jacob, E., Bomfim, E. O., Lopes-Junior, L. C., de Lima, R., Santos, M., et al (2017): Fatigue and Health related Quality of Life in Children and Adolescents with Cancer. *Eur J Oncol Nurs*, 29: pp. 39–46.
- Osann, K., Hsieh, S., Nelson, E., Monk, B., Chase, D., Cella, D., Wenzel, L. (2014): Factors associated with poor quality of life among cervical cancer survivors: implications for clinical care and clinical trials. *GynecolOncol* 135(2): pp. 266–272.
- Palestinian Central Bureau of Statistics (2017): Statistical Yearbook of Palestine. (<http://www.pcbs.gov.ps/Downloads/book2238.pdf>, 25.9.2018).
- Palestinian Health Information Center (2017): Medical Report- Nablus: MOH.
- Palestinian Water Authority (2013): Water Quality on the Gaza Strip Municipal Wells. Gaza: Palestine.
- Pan, H., Wu, L., & Wen, S. (2017): Quality of Life and Its Predictors among Children and Adolescents with Cancer, *Cancer Nursing*, 40(5), pp. 343-351.
- Pirri, C., Bayliss, E., Trotter, J., Olver, I. N., Katris, P., Drummond, P., et al (2013): Nausea still the poor relation in antiemetic therapy? The impact on cancer patients' quality of life and psychological adjustment of nausea, vomiting and appetite loss, individually and concurrently as part of a symptom cluster. *Support Care Cancer* 21(3): pp. 735–748.
- Rahimi, S., Soghe, R., Tabri, R., Leili, E. (2014): Related factors with Quality of Life among preschool children with cancer. *J Holist Nurs Midwifery*; 24 (1): pp. 30-39.

- Rodgers, C., Wills-Bagnato, P., Sloane, R., Hockenberry, M. (2015): Health-Related Quality of Life among Children and Adolescents during Hematopoietic Stem Cell Transplant Recovery. *Journal of Pediatric Oncology Nursing*, 32(5), pp. 329-336.
- Rosenberg, A., Orellana, L., Dussel, V., Wolfe, J. (2016): Quality of Life in Children with Advanced Cancer: A Report from the Pediquest Study (TH311C), *Journal of Pain and Symptom Management*, 51(2), p. 324.
- Santos, S., Crespo, C., Canavarro, M. C., & Pinto, A. (2014): Intensity of Treatment and Health-Related Quality of Life in Pediatric Cancer: Findings from the Portuguese Version of Intensity of Treatment Rating Scale 3.0. *Psychology, Community & Health*, 3(3), pp. 158-171.
- Saudi Health Council (2014): Cancer Incidence Report .Saudi Arabia: Saudi Cancer Registry.
- Sedgwick, P. (2014): Cross sectional studies: Advantages and disadvantages. *Bmj*, p. 348.
- Shamallakh, A., Imam, A. (2017): Quality of life in patients with cancer in the Gaza Strip: a cross-sectional study. *The Lancet*, 390, S21.
- Simon, A. E., Chan, K. S., & Forrest, C. B. (2008): Assessment of Children Health-Related Quality of Life in the United States With a Multidimensional Index. *Pediatrics*, 121(1)
- Skaik, N., Hamad, B. A., Abu-Odah, H. (2016): Evaluation of Palliative Care Services Provided to Cancer Patients in the Gaza Strip. *China Medical Science*, 13(2016): pp. 95-107.

- Theofilou, P. (2013): Quality of Life: Definition and Measurement, *Europe's Journal of Psychology*, 9(1), pp.150-162.
- Thweib, N. (2011): Quality of Life of Palestinian Cancer Patients. *Journal of Pediatric Hematology/Oncology*, Vol 33, P.P 68–S69.
- United Nations Children's Emergency Fund (2014): Convention on the Rights of the Child. (<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>, 20.11.2017).
- United Nations Office for the Coordination of Humanitarian Affairs – OCHA (2018): (<https://www.ochaopt.org/location/gaza-strip>, 12.7. 2018).
- United Nations Relief and Work Agency for Palestine Refugees in the Near East (2016): UNRWA: WHERE WE WORK. (<https://www.unrwa.org/where-we-work/gaza-strip>, 17.11.2017).
- K., A. V., Onta, M., & Joshi, S. (2017): Quality of Life of Nepalese Children With Leukemia Using Pediatric Quality of Life Inventory 4.0 Generic Core Scale. *Journal of Pediatric Oncology Nursing*, 34(5), pp. 322-330.
- Riel, C. A., Bergh, E. E., Kemps, H. L., Feuth, T., Schreuder, H. W., Hoogerbrugge, P. M, et al (2014): Self-perception and quality of life in adolescents during treatment for a primary malignant bone tumour. *European Journal of Oncology Nursing*, 18(3), pp. 267-272.
- Varni, J. W., Seid, M., & Kurtin, P. S. (2001): PedsQL™ 4.0: Reliability and Validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in Healthy and Patient Populations. *Medical Care*, 39(8), pp. 800-812.

Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., Dickinson, P. (2002): The PedsQL in pediatric cancer: reliability and validity of the pediatric quality of life inventory generic core scales, multidimensional fatigue scale, and cancer module. *Cancer*, 94(7), pp. 2090-2106.

Varni, J. W., Burwinkle, T. M., Seid, M., Skarr, D. (2003). The PedsQL™* 4.0 as a Pediatric Population Health Measure: Feasibility, Reliability, and Validity. *Ambulatory Pediatrics*, 3(6), pp. 329-341.

Vlahioti, E., Perdikaris, P., Matziou, V. (2016a): Assessment of quality of life of children and adolescents with different types of cancer in all phases of treatment and its completion, *Nursing Children and Young People*, 28(4), pp.89-89.

Vlachioti, E., Perdikaris, P., Megapanou, E., Sava, F., & Matziou, V. (2016b): Assessment of quality of life in adolescent patients with cancer and adolescent survivors of childhood cancer, *Journal for Specialists in Pediatric Nursing*, 21(4), pp.178-188.

World Health Organization (2017): Cancer
(<http://www.who.int/mediacentre/factsheets/fs297/en/>,12.11. 2017).

World Health Organization (2018a): Cancer in Children.
(<http://www.who.int/news-room/fact-sheets/detail/cancer-in-children>,16.10.2018).

World Health Organization (2018b): Health conditions in the occupied Palestinian territory, including east Jerusalem, and in the occupied Syrian Golan.

World Health Organization (2018c): Cancer. (<https://www.who.int/cancer/en/>, 20.10.2018).

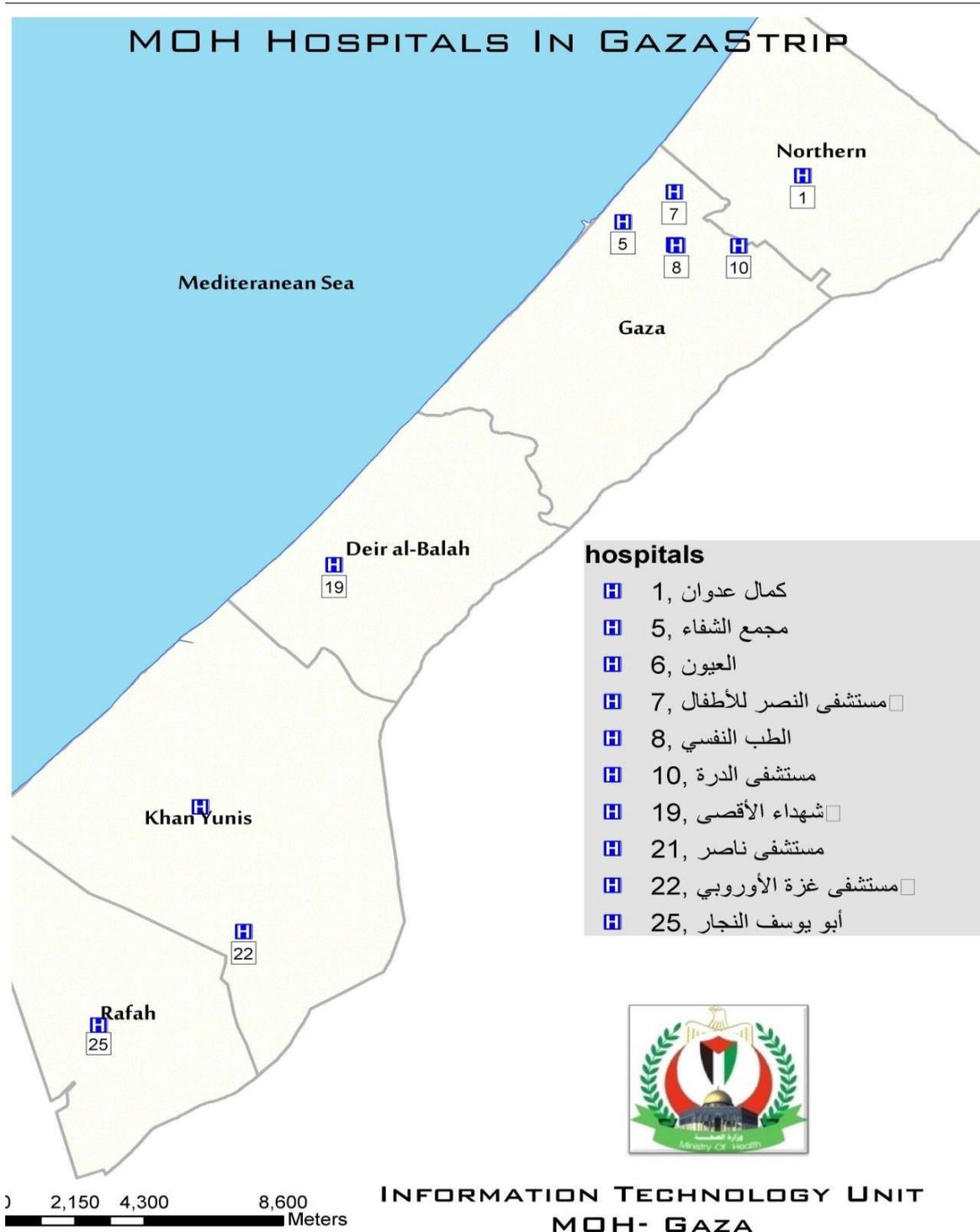
World Health Organization (2012): Introduction the WHOQOL Instrument .Gevna: WHO.

World Health Organization (2014): Gaza Strip: Joint Health Sector Assessment Report

http://apps.who.int/gb/ebwha/pdf_files/WHA66/A66_R5-en.pdf,12,12,2017).

Yağc-Küveli, B., Akyüz , C., Küveli, S., Büyükpamukçu, M. (2012): Health-related Quality of Life in Pediatric Cancer Survivors, *Journal of Pediatric Hematology / Oncology*, 34(3), pp.194-199.

Annex (2) MOH Hospitals in Gaza Strip



Annex (3) Consent form

نموذج موافقة

عزيزي/عزيزتي

تحية طيبة وبعد.

نأمل من سيادتكم التكرم بالموافقة على مشاركة ابنائكم في تعبئة هذا الاستبيان والذي يهدف الي تقييم جودة الحياة لدى الأطفال الذين يعانون من السرطان في مستشفيات قطاع غزة.

ستتم هذه الدراسة من خلال جمع البيانات من المقابلة الشخصية وتعبئة الاستبانة، ومن المقدر أن تستغرق المقابلة 15 - 20 دقيقة وستكون لمرة واحدة مع كل شخص.

يجب أن يكون واضحا لديكم بأن المقابلة لن تتم الا بموافقتك وسيكون لك الحق في قبول أو رفض الاجابة عن الاسئلة، كما ستحترم سرية المعلومات التي سيدلى بها ولن تنشر هذه الدراسة أي أسماء أو عناوين أو أن يلمح بشي من ذلك.

ستفيد نتائج الدراسة في تحديد وتقييم المشاكل والثغرات المتعلقة بجودة الحياة لدى الأطفال الذين

يعانون من السرطان ، مما يساعد على تحسين الجهود التي من شأنها تحسين جودة الحياة وجودة الخدمات وما هي الاحتياجات اللازمة لهؤلاء المرضى.

ليست هذه الدراسة ممولة من أي جهة كانت ، ولا تستهدف تحقيق مكاسب مادية، ولن يترتب عليك أي التزامات مادية معينة.

شاكرين لكم حسن تعاونكم،،،

الطالب/ محمد رياض أبور ريال

Annex (4) Socioeconomic and Demographic Information

المعلومات الشخصية:

- 1- التسلسل:
- 2- المستشفى: الرنتيسي الأوروبي
- 3- العمر:
- 4- الجنس: ذكر أنثى
- 5- مكان سكنك الحالي: محافظة غزة محافظة الوسطى محافظة الشمال محافظة خانينونس محافظة رفح
- 6- عدد الأخوة و الأخوات:
- 7- الأب يعمل: نعم لا
- 8- الأم تعمل: نعم لا
- 9- دخل الأسرة الشهري: شيكل.
- 10- المؤهل العلمي للاب: ابتدائي اعدادي ثانوي جامعي أخرى.
- 11- المؤهل العلمي للام: ابتدائي اعدادي ثانوي جامعي أخرى.

التاريخ المرضي:

- 12- المرض الحالي: امراض الكلى أمراض القلب أمراض الاعصاب أمراض الدم والأورام أمراض الجهاز الهضمي أخرى:
- 13- عدد سنوات تشخيص المرض الحالي:
- 14- هل هناك تاريخ مرضي في العائلة مصاب بالسرطان: نعم لا - اذا كانت الإجابة نعم، ما صلة القرابة:
- أب أم أخ أخت أخرى:

Annex (5) Helsinki committee approval letter



المجلس الفلسطيني للبحوث 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: 05/02/2018 **Number: PHRC/HC/314/18**

Name: MOHAMMED R. ABUREYALA **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:**

Quality of Life among Children with Cancer in Gaza Strip

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/314/18 in its meeting on 05/02/2018 **و قد قررت الموافقة على البحث المذكور عاليه بالرقم والتاريخ المذكوران عاليه**

Signature

Member



Chairman



Member



General 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:-

E-Mail: pal.phrc@gmail.com

Gaza - Palestine **غزة - فلسطين**
شارع النصر - مفترق العيون

Annex (6) Permission letter of ministry of health NO.1



التاريخ: 25/03/2018
رقم المراسلة 203683

السيد: رامي عيد سليمان العبادله المحترم

مدير عام بالوزارة / الإدارة العامة لتنمية القوى البشرية - /وزارة الصحة

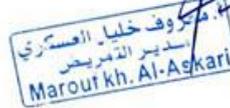
السلام عليكم

الموضوع / تسهيل مهمة الباحث // محمد أبوريالة

التفاصيل //

بخصوص الموضوع أعلاه، يرجى تسهيل مهمة الباحث / محمد رياض أبوريالة الملحق ببرنامج ماجستير التمريض - تخصص تمريض أطفال - جامعة القدس أبوديس في إجراء بحث بعنوان:-
"Quality of Life among Children with Cancer in Gaza Strip"
حيث الباحثة بحاجة لتعبئة استبانة من عدد من مرضى الأورام من الأطفال المراجعين لمستشفى د. عبد العزيز الرنتيسي التخصصي ومستشفى غزة الأوربي.
نأمل توجيهاتكم لذوي الاختصاص بضرورة الحصول على الموافقة المستتيرة من الأطفال وأولياء أمورهم الذين لديهم الاستعداد لمشاركة أطفالهم في الدراسة ومن ثم تمكين الباحث من التواصل معهم، بما لا يتعارض مع مصلحة العمل وضمن أخلاقيات البحث العلمي. ودون تحمل الوزارة أي أعباء أو مسئولية.
وتفضلوا بقبول التحية والتقدير،،،،
ملاحظة البحث حصل على موافقة لجنة أخلاقيات البحث الصحي
ملاحظة / تسهيل المهمة الخاص بالدراسة أعلاه صالح لمدة 5 شهر من تاريخه.

محمد ابراهيم محمد السراوي
مدير دائرة/ الإدارة العامة لتنمية القوى البشرية -



التحويلات

إجراءتكم بالخصوص (25/03/2018)	← رامي عيد سليمان العبادله (مدير عام بالوزارة)	■ محمد ابراهيم محمد السراوي (مدير دائرة)
إجراءتكم بالخصوص (26/03/2018)	← عبد اللطيف محمد محمد الحاج (مدير عام بالوزارة)	■ رامي عيد سليمان العبادله (مدير عام بالوزارة)
إجراءتكم بالخصوص (26/03/2018)	← محمد محمد عبد الحلیم ابو سلميه (مدير مستشفى)	■ عبد اللطيف محمد محمد الحاج (مدير عام بالوزارة)
إجراءتكم بالخصوص (26/03/2018)	← يوسف فوزي اسماعيل العقاد (مدير مستشفى)	■ عبد اللطيف محمد محمد الحاج (مدير عام بالوزارة)
إجراءتكم بالخصوص (26/03/2018)	← سعدي دياب حسن الرملاوي (رئيس قسم مالي)	■ محمد محمد عبد الحلیم ابو سلميه (مدير مستشفى)
إجراءتكم بالخصوص (26/03/2018)	← معروف خليل محمد العسكري (مدير دائرة التمريض)	■ محمد محمد عبد الحلیم ابو سلميه (مدير مستشفى)
لعمل اللازم (26/03/2018)	← حسن عبد المطلب حسين الرفاقي (رئيس قسم اداري)	■ سعدي دياب حسن الرملاوي (رئيس قسم مالي)
لعمل اللازم (26/03/2018)	← كمال صبحي عبدالحميد موسى (مدير اداري)	■ يوسف فوزي اسماعيل العقاد (مدير مستشفى)
لعمل اللازم (26/03/2018)	← اتحاد شكري شاکر شيبير (رئيس قسم اداري)	■ يوسف فوزي اسماعيل العقاد (مدير مستشفى)
لعمل اللازم (26/03/2018)	← عطا اسماعيل خليل الجعبري (مدير دائرة التمريض)	■ يوسف فوزي اسماعيل العقاد (مدير مستشفى)
لعمل اللازم (27/03/2018)	← يحيى عبد القادر رمضان النواجيه (رئيس شعبة اداري)	■ كمال صبحي عبدالحميد موسى (مدير اداري)

Gaza

Tel. (+970) 8-2846949
Fax. (+970) 8-2826295

غزة
تلفون. (+970) 8-2846949
فاكس. (+970) 8-2826295

Annex (7) Permission letter of ministry of health NO.2

Ministry of health



وزارة الصحة
وزارة الصحة

التاريخ: 25/03/2018
رقم المراسلة: 203683

السيد: رامي عيد سليمان العبادلة المحترم

مدير عام بالوزارة /الإدارة العامة لتنمية القوى البشرية - /وزارة الصحة

السلام عليكم ...

الموضوع / تسهيل مهمة الباحث // محمد أبوريالة

التفاصيل //
بخصوص الموضوع أعلاه، يرجى تسهيل مهمة الباحث / محمد رياض أبوريالة
الملحق ببرنامج ماجستير التمريض - تخصص تمريض أطفال - جامعة القدس أبوديس في إجراء بحث بعنوان:-
"Quality of Life among Children with Cancer in Gaza Strip"
حيث الباحث بحاجة لتعبئة استبانة من عدد من مرضى الأورام من الأطفال المراجعين لمستشفى د. عبد العزيز الرنتيسي التخصصي
ومستشفى غزة الأوربي.
نأمل توجيهاً منكم لذوي الاختصاص بضرورة الحضور والتعاون مع الباحثين من الأطفال وأولياء أمورهم الذين لديهم الاستعداد
لمشاركة أطفالهم في الدراسة ومن ثم تمكين الباحثين من التعاون معهم. بما لا يتعارض مع مصلحة العمل وضمن أخلاقيات البحث
العلمي. ودون تحمل الوزارة أي أعباء أو مسئولية.
وتفضلوا بقبول التحية والتقدير...
ملاحظة: البحث حصل على موافقة لجنة اخلاقيات البحث الصحي
ملاحظة / تسهيل المهمة الخاص بالدراسة أعلاه صالح لمدة 5 شهر من تاريخه.

محمد إبراهيم محمد السرساوي
مدير دائرة/الإدارة العامة لتنمية القوى البشرية -



الخاتمة / استرنا نتمنى لدراساتكم
اجرة تسهيل مهمة البحث



التحويلات

إجراء منكم بالخصوص (25/03/2018)	← رامي عيد سليمان العبادلة (مدير عام بالوزارة)	✶ محمد إبراهيم محمد السرساوي (مدير دائرة)
إجراء منكم بالخصوص (26/03/2018)	← عبد اللطيف محمد محمد الحاج (مدير عام بالوزارة)	✶ رامي عيد سليمان العبادلة (مدير عام بالوزارة)
إجراء منكم بالخصوص (26/03/2018)	← محمد محمد عبد الحليم أبو سلمية (مدير مستشفى)	✶ عبد اللطيف محمد محمد الحاج (مدير عام بالوزارة)
إجراء منكم بالخصوص (26/03/2018)	← يوسف فوزي اسماعيل العقاد (مدير مستشفى)	✶ عبد اللطيف محمد محمد الحاج (مدير عام بالوزارة)
إجراء منكم بالخصوص (26/03/2018)	← شعدي دياب حسن الرملوي (رئيس قسم مالي)	✶ محمد محمد عبد الحليم أبو سلمية (مدير مستشفى)
إجراء منكم بالخصوص (26/03/2018)	← معروف خليل محمد العسكري (مدير دائرة التمريض)	✶ محمد محمد عبد الحليم أبو سلمية (مدير مستشفى)
لعمل اللازم (26/03/2018)	← حسين عبد المطلب حسين الرفاقي (رئيس قسم اداري)	✶ شعدي دياب حسن الرملوي (رئيس قسم مالي)
لعمل اللازم (26/03/2018)	← كمال صبحي عبدالحميد موسى (مدير اداري)	✶ يوسف فوزي اسماعيل العقاد (مدير مستشفى)
لعمل اللازم (26/03/2018)	← نهاد شكري شاكور شير (رئيس قسم اداري)	✶ يوسف فوزي اسماعيل العقاد (مدير مستشفى)
لعمل اللازم (26/03/2018)	← عماد اسماعيل خليل الجعبري (مدير دائرة التمريض)	✶ يوسف فوزي اسماعيل العقاد (مدير مستشفى)
لعمل اللازم (27/03/2018)	← يحيى عبد القادر رمضان التراجحة (رئيس شعبة اداري)	✶ كمال صبحي عبدالحميد موسى (مدير اداري)

Gaza

Tel. (+970) 8-2846949
Fax. (+970) 8-2826295

شقة تلفون: 8-2846949 (+970)
فاكس: 8-2826295 (+970)

Annex (8) Permission letter of ministry of health NO.3

STATE OF PALESTINE
Ministry of health



دولة فلسطين
وزارة الصحة

التاريخ: 03/04/2018
رقم المراسلة 206364

السيد : رامي عيد سليمان العبادله المحترم

مدير عام بالوزارة /الإدارة العامة لتنمية القوى البشرية - /وزارة الصحة

السلام عليكم

الموضوع/ تسهيل مهمة الباحث// محمد أبوريالة

التفاصيل //

بخصوص الموضوع أعلاه، يرجى تسهيل مهمة الباحث/ محمد رياض أبوريالة
الملتحق ببرنامج ماجستير التمريض - تخصص تمريض أطفال- جامعة القدس أبوديس في إجراء بحث بعنوان:-
"Quality of Life among Children with Cancer in Gaza Strip"
حيث الباحث بحاجة لبعض الاحصائيات الخاصة بمرضى السرطان من الأطفال من مركز المعلومات الصحية.
نأمل توجيهاتكم لذوي الاختصاص بضرورة عدم إعطاء الباحث اية معلومات شخصية للمرضى (الاسم-رقم الهوية- وسائل اتصال
بالأطفال أو ذويهم)، بما لا يتعارض مع مصلحة العمل وضمن أخلاقيات البحث العلمي، ودون تحمل الوزارة أي أعباء أو مسئولية.
وتفضلوا بقبول التحية والتقدير،،،
ملاحظة/ البحث حصل على موافقة لجنة اخلاقيات البحث الصحي
ملاحظة / تسهيل المهمة الخاص بالدراسة أعلاه صالح لمدة 2 شهر من تاريخه.

محمد إبراهيم محمد السرساوي

مدير دائرة/الإدارة العامة لتنمية القوى البشرية -



التحويلات

إجراء منكم بالخصوص (03/04/2018)	← رامي عيد سليمان العبادله (مدير عام بالوزارة)	■ محمد ابراهيم محمد السرساوي (مدير دائرة)
إجراء منكم بالخصوص (03/04/2018)	← مدحت محمد يوسف مجيب (وكيل وزارة مساعد)	■ رامي عيد سليمان العبادله (مدير عام بالوزارة)
إجراء منكم بالخصوص (03/04/2018)	← خالد حمدي خليل الدهشان (مدير عام بالوزارة)	■ مدحت محمد يوسف مجيب (وكيل وزارة مساعد)
إجراء منكم بالخصوص (03/04/2018)	← هاني سلطان ارميح الوحيددي (مدير وحدة)	■ مدحت محمد يوسف مجيب (وكيل وزارة مساعد)

Gaza

Tel. (+970) 8-2846949
Fax. (+970) 8-2826295

تلفون. (+970) 8-2846949
فاكس. (+970) 8-2826295

غزة

Annex (9) Approval Letter for using PedsQL core 4.0 and PedsQL 3.0 cancer Module



User agreement
Special Terms

Mapi Research Trust, a non-for-profit organization subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as "MRT" and the User, as defined herein, (each referred to singularly as a "Party" and/or collectively as the "Parties"), do hereby agree to the following User Agreement Special and General Terms:

Mapi Research Trust
PROVIDE™
27 rue de la Villette
69003 Lyon
France
Phone: +33 (0)4 72 13 66 66

Recitals

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by MRT for use only in accordance with the terms and conditions defined herein. MRT reserves all rights not expressly granted to the User.

In this respect, the Parties have agreed as follows:

Article 1. Conditions Specific to the User

Section 1.01 Identification of the User

User Name	Mohammed Reyala
Legal Form	Student
Address	Gaza City 90612 Al Quds
Country	Palestinian Territory, Occupied
Email address	Moh.Reyala386@gmail.com

Section 1.02 Identification of the Questionnaire

Title	Pediatric Quality of Life Inventory™ (PedsQL™) and PedsQL™ Cancer module
Author(s)	Varni JW
Owner	Varni James W, PhD
Copyright	Copyright © 1998 JW Varni, Ph.D. All rights reserved
Original bibliographic references	See Appendix 2

Article 2. Territories and Languages

MRT transfers the Limited Rights to use the Questionnaire on the following territories and in the languages indicated in the table below:

Questionnaire	Language
PedsQL™ Cancer module	Arabic for Palestine
PedsQL™ Generic Core Scales	Arabic for Palestine

Article 3. Rights to Use

Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter.

Context of Use	Individual clinical practice
----------------	------------------------------

Thank you again for your interest in this COA!

Should you have any questions, please contact us at eprovide@mapi-trust.org.

Best regards,
Mapi Research Trust

2/2

Pediatric Quality of Life Inventory™_UserAgreement_March2016_22.0

© Mapi Research Trust. The unauthorized modification and use of any portion of this document is prohibited.

Annex (10) PedsQL™ Pediatric Quality of Life Inventory Version 4.0 -

English

INSTRUCTIONS
<p>On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you over the PAST MONTH by circling:</p> <p style="text-align: center;"> 0 if it is never a problem 1 if it is almost never a problem 2 if it is sometimes a problem 3 if it is often a problem 4 if it is almost always a problem </p> <p>There are no right or wrong answers. If you do not understand a question, please ask for help.</p>

Over the PAST MONTH, how much of a problem has this been for you..

ABOUT MY HEALTH AND ACTIVITIES <i>(problems with...)</i>	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to walk more than a couple of streets (about 100 meters)	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activities or exercise	0	1	2	3	4
4. It is hard for me to lift heavy things	0	1	2	3	4
5. It is hard for me to have a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I have aches and pains	0	1	2	3	4
8. I feel tired	0	1	2	3	4
ABOUT MY FEELINGS <i>(problems with...)</i>	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4
HOW I GET ON WITH OTHERS <i>(problems with...)</i>	Never	Almost Never	Some- times	Often	Almost Always

1. I have trouble getting on with other children	0	1	2	3	4
2. Other children do not want to be my friend	0	1	2	3	4
3. Other children tease me	0	1	2	3	4
4. I cannot do things that other children my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other children	0	1	2	3	4
ABOUT SCHOOL (<i>problems with...</i>)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my school work	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

Annex (11) PedsQL™ Pediatric Quality of Life Inventory Version 4.0 -

Arabic

استبيان جودة الحياة لدى الأطفال المصابون بالسرطان

على الصفحة التالية قائمة بأشياء قد تكون مشكلة لك، الرجاء اخبارنا حجم المشكلة لكل منها خلال الشهر الماضي

بوضع دائرة حول (0) إذا "لم تكن أبدا" مشكلة، (1) إذا "تقريبا" لم تكن أبدا" مشكلة، (2) إذا كانت "أحيانا" مشكلة، (3)

إذا كانت "غالبا" مشكلة (4) إذا كانت "تقريبا" دائما" مشكلة.

الأداء الجسدي (مشاكل مع...)	أبدا	تقريبا "أبدا"	أحيانا	غالبا	تقريبا "دائما"
1. أستطيع السير لمدة تتجاوز العشر دقائق	0	1	2	3	4
2. من الصعب أن أركض	0	1	2	3	4
3. من الصعب علي ان امارس النشاط الرياضي او التمارين	0	1	2	3	4
4. من الصعب علي رفع شيء ثقيل	0	1	2	3	4
5. من الصعب علي ان استحم بنفسي أو أغتسل بدون مساعدة	0	1	2	3	4
6. من الصعب علي ان اقوم بأعمال منزلية	0	1	2	3	4
7. أحس بالألم أو اتوجع	0	1	2	3	4
8. أحس أن طاقتي قليلة	0	1	2	3	4
الأداء العاطفي (مشاكل مع...)	أبدا	تقريبا "أبدا"	أحيانا	غالبا	تقريبا "دائما"
9. أحس بالخوف أو الرعب	0	1	2	3	4
10. أحس بالحزن أو الإحباط	0	1	2	3	4
11. أحس بالغضب	0	1	2	3	4
12. أعاني من صعوبة بالنوم	0	1	2	3	4

4	3	2	1	0	13. احس بالقلق لما يمكن ان يحصل لي
تقريبا "دائما"	غالبا	أحيانا	تقريبا "أبدا"	أبدا	الأداء الاجتماعي (مشاكل مع...)
4	3	2	1	0	14. عندي مشاكل في التعامل مع الأطفال الآخرين
4	3	2	1	0	15. أقراني لا يريدون أن يكونوا اصدقاء لي
4	3	2	1	0	16. الأطفال الاخرون يضايقوني أو يسخرون مني
4	3	2	1	0	17. لا استطيع القيام بأمر يستطيع القيام بها من هم في عمري
4	3	2	1	0	18. من الصعب مجارة أقراني
تقريبا "دائما"	غالبا	أحيانا	تقريبا "أبدا"	أبدا	الأداء المدرسي (مشاكل مع...)
4	3	2	1	0	19. من الصعب التركيز في الفصل
4	3	2	1	0	20. انسى الاشياء
4	3	2	1	0	21. أعاني من صعوبة في متابعة واجباتي الدراسية
4	3	2	1	0	22. اتغيب عن المدرسة لشعوري بالتعب
4	3	2	1	0	23. اتغيب عن المدرسة للذهاب الى المستشفى او الطبيب

Annex (12) PedsQL 3.0 cancer Module Version 3.0 - English

DIRECTIONS

Children with cancer sometimes have special problems. Please tell us **how much of a problem** each one has been for you during the **past one month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.

In the past **one month**, how much of a **problem** has this been for you ...

PAIN AND HURT (<i>problems with...</i>)	Never	Almost Never	Some-times	Often	Almost Always
1. I ache or hurt in my joints and/or muscles	0	1	2	3	4
2. I hurt a lot	0	1	2	3	4
NAUSEA (<i>problems with...</i>)	Never	Almost Never	Some-times	Often	Almost Always
1. I become sick to my stomach when I have medical treatments	0	1	2	3	4
2. Food does not taste very good to me	0	1	2	3	4
3. I become sick to my stomach when I think about medical treatments	0	1	2	3	4
4. I feel too sick to my stomach to eat	0	1	2	3	4
5. Some foods and smells make me sick to my stomach	0	1	2	3	4
PROCEDURAL ANXIETY (<i>problems with...</i>)	Never	Almost Never	Some-times	Often	Almost Always
1. Needle sticks (i.e. injections, blood tests, IV's) hurt	0	1	2	3	4
2. I get scared when I have to have blood tests	0	1	2	3	4
3. I get scared about having needle sticks (i.e. injections, blood tests, IV's)	0	1	2	3	4

TREATMENT ANXIETY (<i>problems with...</i>)	Never	Almost Never	Some- times	Often	Almost Always
1. I get scared when I am waiting to see the doctor	0	1	2	3	4
2. I get scared when I have to go to the doctor	0	1	2	3	4
3. I get scared when I have to go to the hospital	0	1	2	3	4
WORRY (<i>problems with...</i>)	Never	Almost Never	Some- times	Often	Almost Always
1. I worry about side effects from medical treatments	0	1	2	3	4
2. I worry about whether or not my medical treatments are working	0	1	2	3	4
3. I worry that my cancer will come back or relapse	0	1	2	3	4
COGNITIVE PROBLEMS (<i>problems with...</i>)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to figure out what to do when something bothers me	0	1	2	3	4
2. I have trouble solving math problems	0	1	2	3	4
3. I have trouble writing school papers or reports	0	1	2	3	4
4. It is hard for me to pay attention to things	0	1	2	3	4
5. It is hard for me to remember what I read	0	1	2	3	4
PERCEIVED PHYSICAL APPEARANCE (<i>problems with...</i>)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel I am not good looking	0	1	2	3	4
2. I don't like other people to see my scars	0	1	2	3	4
3. I am embarrassed when others see my body	0	1	2	3	4
COMMUNICATION (<i>problems with...</i>)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3. It is hard for me to explain my illness to other people	0	1	2	3	4

Annex (13) PedsQL 3.0 cancer Module Version 3.0 – Arabic

استبيان حول جودة الحياة الصحية لدى الأطفال المصابون بالسرطان

على الصفحة التالية قائمة بأشياء قد تكون مشكلة لك، الرجاء اخبارنا حجم المشكلة لكل منها خلال الشهر الماضي

بوضع دائرة حول (0) إذا "لم تكن أبدا" مشكلة، (1) إذا "تقريباً" لم تكن أبدا" مشكلة، (2) إذا كانت "أحياناً" مشكلة، (3)

إذا كانت "غالباً" مشكلة (4) إذا كانت "تقريباً" دائماً" مشكلة.

الوجع والألم (مشاكل مع...)	أبدأ	تقريباً "أبدأ"	أحياناً	غالباً	تقريباً دائماً
1. أشعر بالألم في المفاصل أو في المفاصل والعضلات	0	1	2	3	4
2. أتألم كثيراً	0	1	2	3	4
الغثيان (مشاكل مع...)	أبدأ	نادراً	أحياناً	غالباً	تقريباً دائماً
3. أشعر بالألم في بطني عندما اتلقى العلاج	0	1	2	3	4
4. مذاق الطعام غير محبب لي	0	1	2	3	4
5. أشعر بالألم في بطني عند التفكير في العلاج الطبي	0	1	2	3	4
6. أشعر بالألم في بطني لدرجة تمنعني عن الطعام	0	1	2	3	4
7. بعض الأطعمة والروائح تشعرني بالألم في بطني	0	1	2	3	4
توتر من الإجراءات (مشاكل مع...)	أبدأ	نادراً	أحياناً	غالباً	تقريباً دائماً
8. الإبر (مثل الحقن وفحوصات الدم والمحاليل) تسبب لي الألم	0	1	2	3	4
9. أشعر بالخوف عند سحب الدم	0	1	2	3	4
10. أشعر بالتوتر من التعرض للإبر (مثل الحقن وفحوصات الدم والمحاليل)	0	1	2	3	4
خوف/توتر من جراء العلاج (مشاكل مع...)	أبدأ	نادراً	أحياناً	غالباً	تقريباً دائماً
11. أشعر بالتوتر عند انتظار الطبيب	0	1	2	3	4
12. أشعر بالتوتر عند الذهاب للطبيب	0	1	2	3	4
13. أشعر بالتوتر عند الذهاب للمستشفى	0	1	2	3	4
القلق (مشاكل مع...)	أبدأ	نادراً	أحياناً	غالباً	تقريباً دائماً
14. أشعر بالقلق من الآثار الجانبية للعلاج الطبي	0	1	2	3	4
15. أشعر بالقلق حول فعالية العلاجات التي أتناولها	0	1	2	3	4
16. أشعر بالقلق من (إنتشار، تفاقم) مرض السرطان	0	1	2	3	4
مشاكل في المعرفة (مشاكل مع...)	أبدأ	نادراً	أحياناً	غالباً	تقريباً دائماً
17. من الصعب علي معرفة ما يجب عمله عند التعرض لشيء يضايقني.	0	1	2	3	4

4	3	2	1	0	18. أجد صعوبة في حل المسائل الحسابية
4	3	2	1	0	19. أجد صعوبة في كتابة أوراق او تقارير العمل
4	3	2	1	0	20. من الصعب علي الانتباه للأشياء
4	3	2	1	0	21. من الصعب علي تذكر ما أقرأه
تقريباً دائماً	غالباً	أحياناً	نادراً	أبداً	المظهر الخارجي (مشاكل مع...)
4	3	2	1	0	22. أشعر بأنني لست حسن المظهر
4	3	2	1	0	23. لا أحب أن يرى الآخرون ندباتي
4	3	2	1	0	24. أشعر بالخجل من أن يرى الآخرون جسمي
تقريباً دائماً	غالباً	أحياناً	نادراً	أبداً	التواصل (مشاكل مع...)
4	3	2	1	0	25. أجد صعوبة في أخبار الأطباء أو التمريض بما أشعر به
4	3	2	1	0	26. أجد صعوبة في توجيه أسئلة للأطباء أو التمريض
4	3	2	1	0	27. أجد صعوبة في شرح مرضي للآخرين

Annex (14) Time Table

Activity / Duration	Duration	Nov. 11	Dec. 12	Jan. 1	Feb. 2	Mar. 3	Apr. 4	May. 5	Jun. 6	Jul. 7	Aug. 8	Sep. 9
Development Proposal	2months											
Taking approval from Helsinki	3 weeks											
Taking approval from ministry of health	3 weeks											
Instrument development	month											
Pilot study	3 weeks											
Data collection	2 months											
Data entry	month											
Data analysis	month											
Data discussion interpretation	month											
Research writing	month											

عنوان الدراسة: تقييم جودة الحياة لدى الأطفال الذين يعانون من السرطان في قطاع غزة.

إعداد: محمد رياض أبو ريالة

إشراف: د. معتصم صلاح و د. محمد الجرجاوي

مقدمة:

يعتبر السرطان واحد من المشاكل الصحية الرئيسية حول العالم. سنويا يتم تشخيص أكثر من 300,000 طفل بالسرطان، هو عبارة عن مجموعة من الأمراض التي تؤثر سلبا على جودة الحياة للأطفال المصابون بالسرطان. حيث ان الناس يعيشون لمدة أطول مما كانت في السابق بعد تشخيص المرض مما يقرب من ست مرات أطول مما كانت عليه الحال قبل 40 عاما. وبالتالي، يجب ان يكون اهتمام متزايد لجودة حياة الأطفال المصابون بالسرطان. لذلك كان الهدف العام من الدراسة هو تقييم جودة الحياة لدى الأطفال المصابون بالسرطان في قطاع غزة.

المنهجية:

أجريت هذه الدراسة الوصفية، التحليلية، النوعية في اثنتين من المستشفيات الرئيسية (الرنيتسي و غزة الأوروبي) لقياس جودة الحياة للأطفال المصابون بالسرطان. حيث استهدفت الدراسة 122 طفلا مصاب بالسرطان والذين تبلغ اعمارهم من 7 الى 18 عاما، وقد تم جمع البيانات من خلال الاستبيانات PedsQL 4.0 generic core scale الخاص بقياس جودة الحياة للأطفال المصابون بالسرطان و PedsQL 3.0 cancer module الخاص بقياس جودة الحياة الصحية لدى الأطفال المصابون بالسرطان.

النتائج:

كشفت النتائج ان متوسط الإجمالي لاستبيان جودة الحياة لدى الأطفال المصابون بالسرطان في غزة 52.53%، حيث ان الأداء الاجتماعي هو الأعلى على الإطلاق 60.98%، تلاه الأداء البدني 52.94%، الأداء المدرسي 48.85%، حيث أن الأداء العاطفي كان الأسوأ على الإطلاق 47.13%. وأظهرت النتائج أيضا ان جودة الحياة الصحية للأطفال المصابون بالسرطان كانت متدنية، وبلغ متوسط الإجمالي لاستبيان جودة الحياة الصحية 48.55%. حيث ان محور الغثيان هو الأعلى على الإطلاق 62.37%، تلاه محور المظهر الخارجي 55.66%، محور المعرفة 3.68%، محور التواصل 50.54%، محور الوجع والألم 48.97%، محور القلق 42.14%، محور التوتر من جراء العلاج من 38.18%، وكان محور التوتر من الإجراءات الأسوأ على الإطلاق 24.38%.

وبينت النتائج ان دخل الاسرة الشهري للمشاركين تحتوي على فروق ذات دلالة إحصائية على جودة الحياة للأطفال المصابون بالسرطان ($p=0.011$)، وايضا تحتوي على فروق ذات دلالة إحصائية على جودة الحياة الصحية للأطفال المصابون بالسرطان ($p=0.014$). وأوضحت الدراسة أيضا ان عدد افراد الأسرة تحتوي على فروق ذات دلالة

إحصائية على جودة الحياة للأطفال المصابون بالسرطان ($p=0.010$)، ولا تحتوي على فروق ذات دلالة إحصائية على جودة الحياة الصحية للأطفال المصابون بالسرطان ($p=0.231$).

وأوضحت الدراسة أيضا ان كلا من الجنس، العمر، المستشفى الذي يحصل فيه الطفل على الرعاية، مكان اقامة المشاركين، لا تحتوي على فروق ذات دلالة إحصائية على جودة الحياة للأطفال المصابون بالسرطان ($p=0.985$)، (0.359 ، 0.477 ، 0.855 ؛ على التوالي)، وايضا لا تحتوي على فروق ذات دلالة إحصائية على جودة الحياة الصحية للأطفال المصابون بالسرطان ($p=0.488$ ، 0.722 ، 0.596 ، 0.620 ؛ على التوالي). علاوة على ذلك، اوضحت النتائج ايضا ان كلا من مستوي تعلم الأب، مستوي تعلم الأم، عدد سنوات المرض، وتاريخ العائلي للمرض لا تحتوي على فروق ذات دلالة إحصائية على جودة الحياة للأطفال المصابون بالسرطان ($p=0.597$ ، 0.094 ، 0.678 ، 0.562 ؛ على التوالي)، وايضا لا تحتوي على فروق ذات دلالة إحصائية على جودة الحياة الصحية للأطفال المصابون بالسرطان ($p=0.526$ ، 0.276 ، 0.827 ، 0.391 ؛ على التوالي).

الخلاصة:

لخصت الدراسة الى ان جودة الحياة للأطفال المصابون بالسرطان في قطاع غزة كانت (52.53%) ، في حين كانت جودة الحياة الصحية لهم (48.55%). وظهرت الدراسة بعض المشاكل التي صادفت الأطفال والتي لا تظهر خلال الفحص الروتيني والدوري لهم. ويتضح من الدراسة ان السرطان يؤثر بشكل سلبي على كل مناحي وجوانب الحياة للأطفال.

التوصيات:

وفقا لانخفاض الظاهر في جودة الحياة للأطفال المصابون بالسرطان في قطاع غزة. تسلط النتائج الضوء على بعض التوصيات المهمة منها:

- تبني برامج والتي من الممكن ان تحسن جودة الحياة.
- دعم نفسي واجتماعي للأطفال وعائلاتهم.
- ارشادات وتوجيهات للمجتمع حول كيفية التعامل مع الأطفال المصابون بالسرطان.
- تحسين اجراءات التحكم وعلاج الالم والقلق.
- توفير وتطوير اجراءات للكشف المبكر للسرطان.
- تطوير موقع الكتروني في فلسطين لزيادة المعرفة والوعي للامة حول سرطان الأطفال.
- تطوير مهارات التواصل لمقدمي الخدمات الصحية للأطفال.