بسم الله الرحمن الرحيم

* * *

شبكة المعلومات الجامعية
التوثيق الإلكتروني والميكروفيلم

جامعة عين شمس

التوثيق الإلكتروني والميكروفيلم

قسم

نقسم بالله العظيم أن المادة التي تم توثيقها وتسجيلها
علي هذه الأقراص المدمجة قد أعدت دون أية تغيرات

يجب أن

تحفظ هذه الأقراص المدمجة بعيدا عن الغبار

* * *

MONA MAGHRABY

شبكة المعلومات الجامعية

التوثيق الالكتروني والميكروفيلم

* * *

MONA MAGHRABY

Assessment of Parental Caring for Children with Cancer on Their Quality of Life

(An Assessment Study)

Thesis

Submitted for Partial Fulfillment of the Requirement of Master Degree in Pediatric Nursing

By

Mona Ahmed Ewais
(B. Sc. Nursing / 2006)
Faculty of nursing, (Assiut University)
Nursing Supervisor in National Cancer Institute

Faculty of Nursing
Ain Shams University
2020

Acknowledgments

First and for most, I feel always indebted to **Allah** *the Most kind and most Merciful.*

I wish to exprees my deepest thanks and sincere appreciation **Prof.Dr. Zeinab Fathy ELsyed,** *Assistant Professor of Pediatric Nursing, Faculty of Nursing, Ain Shams University, for her great support and advice, her valuable remarks gave me the confidence and encouragement to fulfill this work.*

I also my special gratitude and appereciation to **Dr. Mona Mohamed Hafez,** *lecturer of Pediatric Nursing, Faculty of Nursing, Ain Shams University for her contructie supervision, co-operation and direction that throughout this work.*

Finally, I dedicated this work to all children with cancer and their parents. Also I dedicated and gretful this work to all my members of the family.

Mona Ahmed Ewis

Title Page No.

List of Contents

List of Tables

List of Tables cont...

List of Figures

Figures of Review

Figures of Results

List of Abbreviations

Abb. Full term

Abb.	Full Term
AIDS	Acquired immune deficiency syndrome
ALL	Acute Lymphoblastic Leukemia
AML	Acute Myelogenous Leukemia
BBB	Blood –brain barrier
BRM	Biologic response modifier
CHOP	Cyclophamide, doxorubicin, oncovin, and prednisone
CLL	Chronic Lymphocytic Leukemia
CML	Chronic Myelogenous Leukemia
CNS	Central Nervous System
CSF	Cerebrospinal Fluid
CT	Computed Tomography
DNA	Deoxyribonucleic Acid
GSM	Global system for mobil communication
HIV	Human Immunodeficiency Virus
HL	Hodgkin Lymphoma
HLA	Human leukocyte antigen
HRQOL	Health-Related Quality Of Life
IARC	International agency for research on cancer
JMML	Juvenile Myelomonocytic Leukemia
LM	Lymphomatous Meningitis
MRI	Magnetic resonance imaging
NCI	National Cancer Institute
NHL	Non-Hodgkin Lymphoma
QOL	Quality of Life
R-CHOP	Rituximab-Cyclophamide, doxorubicin, oncovin, and prednisone
US	United states
UVB	Ultraviolet B
WHO	World Health Organization

INTRODUCTION

The diagnosis of cancer in children and adolescents is a life-altering event for them and their families. Although advances in treatment have increased the overall 5 years' survival rate for childhood cancers to approximately 80%, cancer is still the second leading cause of death following accidents in children aged from eight to eighteen years old. The types of cancers that develop in children and adolescents differ from those developed in adults ***(Granek et al., 2014)***.

The incidence of cancer in children that more than 175.000 every year, and the mortality rate is approximately 96.000 every year. In United States 100.000 child and teens were diagnosed with cancer and 1.300 deaths from cancer among children from one year to fourteen years old. In developed countries, the morality rate from cancer approximately 25% of cases. Furthermore, in low setting, resources the mortality is approximately 80% in the world's poorest countries. In general, the incidence of pediatric cancer is higher in industrializes countries than in developing countries, but patterns differ by cancer type (***National Cancer Institute, 2016).***

One boy in 300 boys and one girl in 333 girls are developing cancer before the age of eighteen years old. The most common malignancy among infants is neuroblastoma, whereas leukemia predominates among 1-4 years old children and central nervous tumors among 5-9 years old children. After the age of 10 years, lymphomas, carcinomas, germ-cell tumors and bone tumors become more frequent and embryonic tumors (retinoblastoma, nephroblastoma, hepatoblastoma) become very uncommon ***(Kushi et al., 2012).***

A minor part of childhood cancers is caused by genetic factors, but the etiology of most childhood cancers remains unknown. Childhood cancers differ markedly from adult cancers in their nature, distribution and prognosis. Carcinomas are most common cancers, whereas hematological malignancies and tumors of the Central Nervous System (CNS) account for the majority of childhood cancers ***(Jayasekara et al., 2016).***

Childhood cancer has extensive consequences and places a heavy physical and psychological burden on the child and its family. Rapid diagnosis helps ensure appropriate and timely therapy and optimizes the chances of cure. Given the severity of childhood cancer and the importance of timely diagnosis, remarkably little is known about how and when these children enter the healthcare system ***(Granek et al., 2014).***

A fundamental problem in early cancer diagnosis is that representing common, transient and harmless conditions, the presenting symptoms of childhood cancer tend to be unspecific and vague. The most common presenting symptoms are fever, headache, vomiting, pallor and fatigue, bone pain, limping, weight loss, bleeding or the presence of a mass/lump ***(Hooke et al., 2013).***

Parents should have given detailed information about the diagnosis and treatment, in addition to the short and long term effects of treatment. Parents must understand the treatment to feel right about investigation and procedure. Furthermore, parents would have to sign treatment consent forms and make important decisions about what would be best for their using child all information given by the primary oncology nurse ***(Ljubojevic &Skerlev, 2014).***

The quality of life of children treated for cancer has become a major focus in the field of pediatric oncology. There is no consensus on the definition of the quality of life. Definitions range from describing the quality of life impact of a person’s health on his or her ability to lead a fulfilling life to those with a holistic emphasis - social, emotional, and physical well-being ***(Han&., Bredart et al., 2013)***

Pediatric nurse has an important role toward the psychosocial problems of children with cancer. Providing support to the children and their families, promoting positive self-concept, promoting coping through the cancer continuum and advocating for complete care to improve quality of life for children with cancer ***(Farjou et al., 2014).***

Significance of the study:

In Egypt, childhood cancer represents a dangerous health problem from birth to adolescence which affects children and their families. According to the statistical department in National cancer institute (NCI) at 2016, there was 2166 child admitted to NCI with different types of cancer (NCI, 2017) ***(Elhfnawy, 2013).***

Moreover, through clinical experiences it was observed that children with cancer suffered from many complications physically, emotionally and socially during care. Needs and expectations of parent's care for children with cancer have been under estimated from oncology nurse and will affect the physical, psychological, and /or social well-being of children and their families. So determining the needs and expectations of parent's care will hopefully help to develop supportive strategy for caring of parents and children with cancer. This study would contribute to better understanding of parents of cancer child needs and expectations from nurses.

AIM OF THE STUDY

The study aimed to assess parental caring for children with cancer on their quality of life through:

- Assessment of the characteristic of children with cancer and their parents.
- Assessment of knowledge and reported practice of parents about cancer disease and its manegment.
- Assessment of quality of life among childrenwith cancer

Research question:

1- What are the knowledge and practice of parents about the care of children with cancer?

2- What is the level of quality of life for children with cancer?