Study of Health-related quality of life
in childhood cancer survivors

Thesis

Submitted for Partial
Fulfillment of Master
Degree in Pediatrics

By

Rasha Kobise Kassem
M.B.,B.Ch.

Under Supervision Of

Prof. Dr. Farida El Baz Mohamed
Professor of Pediatrics
Faculty of Medicine
Ain Shams University

Dr. Mohamed El Sayed M. Mowafi
Lecturer of Pediatrics
Faculty of Medicine
Ain Shams University

Dr. Amany Mohamed Ali
Lecturer of Pediatric Oncology
South Egypt Cancer Institute
Assiut University

FACULTY OF MEDICINE
AIN SHAMS UNIVERSITY
2010

Acknowledgements

First and foremost, thanks to Allah “the most merciful”.

I would like to express my most gratitude to **Prof. Dr. Farida El Baz**, Professor of Pediatrics - Faculty of Medicine – Ain Shams University, for giving me the privilege of working under her meticulous supervision and for her great constant support, generous guidance and encouragement.

I also owe my deep thanks and gratitude to **Dr. Mohamed El Sayed M. Mowafi** Lecturer of Pediatrics - Faculty of Medicine – Ain Shams University, for his great patience, support and fruitful comments.

My sincere thanks and appreciation area also to **Dr. Amany Mohamed Ali** Lecturer of Pediatric Oncology - South Egypt Cancer Institute – Assiut University, for her great help , guidance and significant encouragement.

Rasha kobise

Dedication

To the memory of my dear father for his endless love and for his patience
and struggle against cancer;
to my mother for her trust and selfless love;
to my husband for his support, love and encouragement and
to our beloved daughter Gannah, the light of our life;
to all my family especially my promising sister,Heba.

In particular, I dedicate this thesis to the memory of those children for whom
our knowledge was insufficient;
to those children who have been cured but must approach adult life with the
residua of treatment;
and to the children of the future who will benefit from scientific advances
that may limit treatment toxicity so as to truly approach cure.

Rasha kobise

Index

List of Tables

Tables of the Review:

Tables of the Results

List of Figures

Figures of the Review

Figures of the Result

List of Abbreviations

CDI	**Children Depression Inventory**
HADS	**Hospital Anxiety and Depression Scale**
HRQOL	**Health Related Quality of Life**
MCS	**Mental Component Summary**
PCS	**Physical Component Summary**
PTSD	**Post traumatic Stress Disorder**
QOL	**Quality of Life**
ICCC	**International Classification of Childhood Cancers**
SEER	**Surveillance, Epidemiology, and End Results Programme**
CCSS	**The Childhood Cancer Survivor Study**
ALL	**acute lymphoblastic leukemia**
NHL	**non- Hodgkin's lymphoma**
HD	**Hodgkin's disease**
MDS	**Myelodysplastic syndrome**
AML	**Acute myeloid leukemia**
RMS	**Rhabdomyosarcoma**
NB	**Neuroblastoma**
CDC	**Centers for Disease Control and Prevention**
EORTC	**The European Organization for the Research and Treatment of Cancer**
SAD	**Separation anxiety disorder**
GAD	**generalized anxiety disorder**

BMT	**Bone marrow transplantation**
NCCN	**National Comprehensive Cancer Network**

Introduction

Survival rates of children with cancer have increased dramatically over the last decades. Today approximately two thirds of children with cancer survive their illness. In the developed countries, about 1 in every 1,000 adults reaching the age of 20 will be a long-term cancer survivor (**Last et al., 2005**).

In the 1960s most children with cancer died. The 5-year survival rate was only 28%, Now three out of four children diagnosed with a malignancy in childhood will survive the disease and treatment (**Patenaude et al., 2005**).

Survival from cancer has seen dramatic improvements over the past three decades, mainly as a result of advances in early detection, therapeutic strategies, and the widespread use of combined modality therapy (surgery, chemotherapy, and radiotherapy). Medical and sociocultural factors such as psychosocial and behavioral interventions, active screening behaviors, and healthier lifestyles may also play an integral role in the length and quality of that survival **(Ganz, 2007).**

The progress in medical care has changed the focus of research in pediatric psycho-oncology from descriptions of the impact of an impending death of the child to the impact on the quality of life (QOL) of the child and the family during and after treatment (**Last et al., 2005**).

In general, cancer survivors' quality of life concerns the assessing of their physical, psychological, social and spiritual well being **(Hewitt et al., 2006**).

The psychosocial functioning of childhood cancer survivors are described in terms of quality of life dimensions, cognitive functioning, scholastic competence, peer acceptance, physical well-being, future expectations, and parents attitudes (**Samardakiewicz et al.,2007)**.

Recently, the role of socio-cultural features was found to play a role in the psychosocial adaptation after completion of cancer therapy. Patients living in rural areas may be less privileged in this aspect from those in urban areas **(Samardakiewicz et al., 2007**).

Studies of psychosocial functioning of adult survivors of childhood cancer have shown that 10% to 20% of individuals show signs of psychologic maladjustment in the form of mood disturbances, behavioral problems, and somatic distress **(Zebrack et al., 2002)**.

Although a 5-year period without treatment can be considered as a criterion for survival of childhood cancer, several investigators also consider children with shorter duration of survival. This is due partly to the different survival perspectives for different diagnoses in childhood cancer (**Last et al., 2005**)

Survival will always remain the ultimate goal in treatment of children with cancer. As treatments and clinical outcomes improve, attention needs to be focused on the long-term well-being of the survivors. The ultimate goal is to identify and minimize the negative consequences of childhood cancer and its treatment (**Shankar et al., 2005**).

Aim of the work:

The aim of this study was to assess the health related quality of life(HRQOL) and psychological distress in childhood cancer survivors and comparing them with age and sex matched controls.