Faculty of Medicine
Ain Shmas University

Do Long-term Survivors of Childhood Cancer Receive Recommended Medical Care? Self Audit of Pediatric Hematology/Oncology Specialized Clinic, Ain Shams University Hospitals

A thesis

Submitted For Partial Fulfillment of
Master Degree in Pediatrics

Presented by

Ibrahim Sayed Ibrahim Saad
(M.B. B.Ch)
Faculty of Medicine - Ain Shams University

Under Supervision of

Professor. Safinaz Adel Elhabashy
Professor of Pediatrics
Faculty of Medicine - Ain Shams University

Assist. Professor Samar Mohamed Farid
Assistant Professor of Pediatrics
Faculty of Medicine – Ain Shams University

Faculty of Medicine - Ain Shams University
2012

كلية الطب– جامعة عين شمس

هل يتلقي الأطفال المتعافين من السرطان الرعاية الصحية الموصي لهم بها؟ دراسة لتقييم جودة الرعاية الصحية المقدمة للمتعافين من السرطان بعيادة أمراض دم و أورام الأطفال بمستشفيات جامعة عين شمس

رسالة مقدمة من

الطبيب/ إبراهيم سيد إبراهيم سعد

بكالوريوس الطب والجراحة

كلية الطب– جامعة عين شمس

توطئة للحصول على درجة الماجستير في طب الأطفال

تحت إشراف

أ.د/ سافيناز عادل الحبشي

أستاذ طب الأطفال

كلية الطب- جامعة عين شمس

أ.م.د/ سمر محمد فريد

أستاذ مساعد طب الأطفال

كلية الطب - جامعة عين شمس

كلية الطب - جامعة عين شمس

٢٠١٢

بِسْمِ اللّهِ الرَّحْمنِ الرَّحِيمِ

" وَاتَّقُواْ اللّهَ وَيُعَلِّمُكُمُ اللّهُ

وَاللّهُ بِكُلِّ شيءٍ عَلِيمٌ "

صدق الله العظيم

سورة البقرة (الآية٢٨٢)

Faculty of Medicine - Ain Shams University

Vision, Mission and Values

Our Vision:

To be the first in the Middle East to produce doctors with competitive edge and lead development of medical education.

Our Mission:

To prepare a graduate with competitive skills on the national and local levels, capable of teaching and learning and training for life and is committed to the standards of medical service and professional ethics. The college also seeks continued development of programs and courses, supports and develops scientific research with the expansion of applied scientific research and health care programs to serve the needs of society and environment development.

Our Values:

We carry out our job aiming at excellence and not just performance, we practice honesty in everything we do, we always strive to achieve equality of rights and the balance between right and duty, with the mutual respect and work together for the benefit of one and all.

Acknowledgement

First of all, I should express my deep thanks to **Allah,** without his great blessing and mercy, I would never accomplish my work, and to whom I relate any success in achieving any progress in my life.

I would like to express my sincere appreciation and deepest gratitude to **Dr. Safinaz Adel El-Habashy** Professor of Pediatrics, Ain Shams University. Every word and every step in this work have been kindly arranged by her sincere effort. I learned a lot of her humanity, patience and thoughts. It was a pleasure and honor to work under her supervision.

I am deeply grateful to **Dr. Samar Mohammed Farid** Assistant Professor of Pediatrics, Ain Shams University for her meticulous advice, continuous encouragement and valuable instructions throughout this work. It was a privilege to work under her guidance.

Special thanks to **Our Patients** and their families for their cooperation with us to achieve this study.

In memory of **My Father** who instilled in me the meaning of family, patience and working hard.

My truthful affection and love to **My Mother** who always requests blessings and happiness to all of us from **Allah**.

To my devoted and patient **Wife**. And finally to my joy and actually my growing dreams, **My Children Judy** and **Malek**.

Ibrahim Sayed

Abstract

Cancer and its treatment may result in a variety of physical and psychosocial effects that predispose childhood cancer survivors to excess morbidity and early mortality when compared with the general population. The quality of health care delivered to the survivors of childhood cancer was assessed in order to ensure that survivors receive the recommended care and ultimately reduce the severity of resultant late effects.

This study included 30 survivors of childhood cancer aging 6 - 18 years (mean age 11.7 ± 3.02 years). They were 12 males (40%) and 18 females. Survivors of acute lymphoblastic leukemia (ALL) were 18 cases (60%), Hodgkin lymphoma survivors were 6 cases (20%) and survivors of Wilms' tumor were 6 cases (20%).

All cases of the three groups had average values regarding weight, height, BMI and height-for-age percentiles. Parents of 27 (90%) cases were satisfied about care givers. In current study information was clearly given to parents regarding long-term follow-up in 27 (90%) cases and parents were involved in decision making in 18 (60%). Of the included 30 survivors, 18 regularly attended the clinic. None of the included cases received service, in adherence to guidelines. In conclusion, despite a significant risk of late effects after cancer therapy, the majority of childhood cancer survivors do not receive recommended risk-based care and do not adhere to scheduled follow up.

Do Long-term Survivors of Childhood Cancer Receive Recommended Medical Care? Self audit of Pediatric Hematology/Oncology Specialized Clinic, Ain Shams University Hospitals

A thesis

Submitted For Partial Fulfillment of

Master Degree in pediatrics

By

Ibrahim Sayed Ibrahim Saad

(M.B.B.Ch)

Ain-Shams University

Under Supervision Of:

Dr. Safinaz Adel Elhabashy

Professor of Pediatrics

Faculty of Medicine- Ain Shams University

Dr. Samar Mohamed Farid

Lecturer of Pediatrics

Faculty of Medicine – Ain Shams University

Faculty of Medicine - Ain Shams University

2009

Introduction

Childhood neoplasms include a diverse array of malignant tumors, and non malignant tumors arising from disorders of genetic processes involved in control of cellular growth and development. Although many genetic conditions are associated with increased risks for childhood cancers, such conditions are believed to account for <5%of all occurrences. Lymphohematopoietic cancers (i.e. acute lymphoblastic leukemia, lymphomas) account for approximately 40%, nervous system cancers for approximately30%, and the embryonal and sarcomas for approximately 10% each among the broad categories of childhood cancers .Although relative 5yr survival rates have improved from 56% in 1974 to >81% in 2000, malignant neoplasms remain the second most common cause of all deaths among persons 1-14yr of age in the USA **(Kadan-Lottick, 2007).**

Prior to the 1970s and the advent and use of multi-modal chemotherapy, children diagnosed with leukemia and other forms of cancer had little hope of long-term survival. Today, advances in treatment and the coordination of pediatric treatment through clinical trials have greatly increased the long-term life chances of these young people. Indeed, recent reports indicate that 75% of children diagnosed with various forms of cancer in the United States are expected to survive their disease and treatment **(Landier et al., 2006).**

Cancer and its treatment predispose childhood cancer survivors to chronic or late occurring health problems that may not become clinically significant until many years after therapy. Frequently, long-term survivors of childhood cancer report late cancer-related effects that diminish quality of

life and increase the risk of early mortality, this is why it is important for all children treated for cancer to get lifelong follow-up **(Zebrack and Zeltzer, 2001).**

Aim of the work:

To ensure that all pediatric cancer survivors receive the recommended survivor care and ultimately reduce the severity of resultant late effects, the quality of health care delivered to survivors of childhood cancer will be assessed.

Study population:

The study will be carried out at Long Term Cancer Survivors Clinic (LTCSC), Hematology/Oncology Department, Children Hospital, Ain shams University. All children and adolescents with cured cancer and at least a year off therapy will be enrolled in the study.

Study design:

A three-part, individualized profile, the plan includes; i) a summary of the survivor's cancer type and treatment history; ii) a late effect risk profile and a recommended surveillance plan according to "gold standard" Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers from the Children's Oncology Group; and iii) patient, parents and health care provider satisfaction.

A) Revision of patients files for the following data:

1- Socio-demographic data (age, sex, socioeconomic status).

2- Onset, type, diagnosis, duration of cancer and age of cure.

3- Protocol of treatment, number of relapses and complications during treatment.

4- Any supportive care given to the patients.

B) Physical examination with special emphasis on:

1-Weight, height and BMI (Egyptian Growth Charts, 2002).

2- Pubertal staging using Tanner maturity scale (Tanner, 1965).

3- Blood pressure measurement.

4- Neurological examination (neuropathy & myopathy).

5-Dental examination.

5-Fundus & slit lamp finding

6-Audiological assessment.

C) Investigations done to the patients and the compliance to follow-up schedule:

1) Complete blood picture.
2) Liver function test
3) Kidney function test
4) ECG & Echo finding.
5) Hormonal assay & any detected endocrinal problem.
6) Pulmonary function test.
7) Radiological evaluation according to the site of lesion.
8) Bone marrow examination & CSF examination.
9) DEXA (dual energy x-ray absorptiometry).

D) Patients& parents interview:

To complete a questionnaire designed to assess current service & get data about breaking the news, and education given. This form is designed to facilitate understanding of the family's circumstances, knowledge of childhood cancer and satisfaction with health care and to identify patient and family concerns. It should be completed by the family and subsequently reviewed with the family by a health care provider.

Health Questionnaire

Name:---------- Age-------- Today's Date -----/-----/-----

Phone Numbers: Home---------- Cellular----------

Who lives with you? ----------

Emergency contact:---------- Relationship:----------

Phone:---------- Address:----------

1- Have your child been seen by any doctor, hospitalized, or had any intervention in the past year ? Yes No ,if yes describe:----------
---

2- Please list all medicines that your child take regularly (whether prescribed by a doctor or not) ----------

3- Does your child have any allergies? Yes No if yes, list:----------
---

4- Have your child had any immunizations (vaccines) within after being off therapy? Yes No if yes, list:----------

5- What is your child's grade in school? ----------

6-Do you feel there is a need for a better understanding of your child's special needs at school? Yes No if yes, describe:----------

---

7- How many days were your child absent during the past school year?

(0-5):-------- (6-10) :-------- (11-20):-------- (more than20):----------

8- Does your child have any academic problems in school? Yes No if yes, describe:----------

9- Does your child have any behavior problems in school? Yes No if yes, describe:----------

10- Does your child exercise or participate in sports?

No:-------

Less than once a week:----------

1 to 2 times a week:----------

3 or more times a week: ----------

11- Does your child have any of the following health problem?

- Often feeling tired Yes No
- Unexplained weight loss Yes No
- Unexplained weight gain Yes No
- Unexplained fevers or night sweat Yes No
- Rashes Yes No
- Changes with skin mole(s) Yes No location:

- New lump(s) Yes No location:

- Easy bruising or bleeding Yes No

- Frequent headaches Yes No

- Wearing glasses Yes No

- Wearing contact lenses Yes No

- Trouble with vision that is not corrected by glasses or by contact lenses

Yes No

- Last eye examination:----------

- Hearing troubles Yes No

- Wearing hearing aids Yes No

- Last hearing examination:----------

- Frequent sinus congestion or (hay fever) Yes No

- Dental problems Yes No

- Last dental examination:----------

- Difficulty swallowing Yes No

- Rapid or irregular heart beats Yes No

- Chest pain Yes No

- Shortness of breath Yes No

- Wheezing Yes No

- Loss of appetite Yes No

- Frequent nausea or vomiting Yes No

- Frequent heart burn Yes No
- Frequent abdominal pain Yes No
- Frequent diarrhea Yes No
- Frequent constipation Yes No
- Blood in stool Yes No
- Pain or burning with urination Yes No
- Need to urinate frequently Yes No
- Blood in urine Yes No
- Joint or bone aches Yes No
- Frequent muscle aches Yes No
- Other frequent pain Yes No
- Tremors of hands Yes No
- Seizures (convulsions) Yes No
- Dizziness Yes No
- Memory problems Yes No
- Often feeling sad or down Yes No
- Often feeling anxious or worried Yes No
- Frequent mood swings Yes No
- Sleeping troubles Yes No
- Smoking cigarettes Yes No
- Does anyone in your home smoke? Yes No

- How would you rate your child overall health?

Excellent ------ Very good ------ Good ------ Fair ------ Poor ------

12- Has anyone in your family been diagnosed with cancer during the past year? Yes No if yes, list family member---------- & age----------

13- Does your child have health assurance?

NO:-------

Through his \ her parent's job:-------

Through his \ her school: ---------

14- Does any of your other children have any problems because of his brother or sister was suffering from cancer? Yes No if yes, describe:----------

15- Females only:

- Have you had a menstrual period during the past year? Yes No if yes, date of last menstruation: ---- \ ---- \ ------

-How often are your periods? Every ------- days

- How long do your periods last? ---------- days

-Is your cycle: regular (----) or irregular (----)

-Is your menstrual flow : light (----) moderate (----) severe (----)

16- Does your child have any other health problems or concerns that have not been addressed in this questionnaire? Yes No if yes, describe:----------