

Health Needs of Children with Leukemia and their Families Adjustment

Thesis

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ABSTRACT

Leukemia is the name given to a group of hematological malignancies affecting the bone marrow and lymphnodes. The present study aimed to identify the health needs of leukemic children and their families adjustment. The study was conducted in out patient of **Abu El-Rish Pediatric Hospital and National Cancer Institute- Cairo University. One hundred and ten** leukemic children and their families have been selected. Data were collected through (١) interviewing questionnaire to assess biopsychosocial needs of leukemic children, (٢) Observation checklist to assess families practices toward their leukemic children, (٣) Adjustment scale to assess families adjustment toward leukemic children illness. Results of this study, the majority of leukemic children more than three quarter feel useless and more than one third of them of leukemic children got virus C infection as one of blood transfusion health problem, care givers practices had satisfactory impact about their leukemic children needs, there was satisfactory correlation between care givers knowledge and their practices but unsatisfactory correlation between care givers education and their adjustment. The study recommended simple Arabic booklet about disease and treatment and near cententers to deal with leukemic children if any emergency situation happened, discharge plan to explain importance of continuation of follow up for treatment, encourage educational programs for the care givers.

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List of Abbreviations

c.g	: care giver .
ALL	: Acute lymphoplastic leukemia.
NCI	: National Cancer Institute.
CNS	: Central Nervous System.
GIT	: Gastro Intestinal Tract.
I.V	Intravenous
ANC	Absolute Neutrophil Count.

Introduction

Acute lymphoblastic leukemia (ALL) accounts for approximately 25% of childhood leukemia's. In this form of the disease the lymphocyte cell line 90% of cases (*Ebra, 2010*).

Around the world annual incidence of acute lymphoblastic leukemia (ALL) is 1 in 60,000 peoples with 70% of patients less than 10 years old, but the AML and ALL have slight male predominance (*Bailey, 2009*).

In the National Cancer Institute *NCI* (2010) the annual incidence of leukemic in males is 2.1% and the females is 0.9%. The median age of patient is approximately 19.5 years.

Before the era of chemotherapy 85% of patient with All died within 8 weeks of the onset of their symptoms, currently the overall survival rate is 70% to 75% and the survival rate for certain low risk patient may be as high as 90% (*Bailey, 2009*).

Chemotherapeutic agents are immunosuppressive and most have significant side-effects, adverse effects, and potential toxic effects which occurring at specific time frames after administration, for example, acute side

effects may appear immediately after to a few days after administration of the agent (*Doborah & Christin, ۲۰۱۱*), intermediate side effects occur within a few weeks after administration and long term effects may occur months to years after administration.

Leukemic children needs physical, psychological, social spiritual care, and the family use the nurse as a resource for informations about disease, treatment protocol and specific side effects of chemotherapy (*Barbor, ۲۰۰۶*).

Families adjustment is adaptation under very difficult conditions they are reacting as adaptively as possible to difficult stressful situation threatening life events, External resources may be helpful in meeting practical and emotional needs of families members of cancer patient is affected by the illness experience (*Kristjanson & Ashcroft, ۲۰۰۳*).

Burke et al (۲۰۰۷) documented that all family members will be affected and can be experience felling of loss of control and uncertaining about their feelinng. Therefore family aw areness toward the disease and its implications will lessen their feeling of anxiety, guilt, anger and they participate in planning their child's care.

Parents are often responsible for the majority of care and support given to their leukemic child. Therefore, it is essential that the families receive an adequate information and awareness about the disease, treatment plans and goals, possible side effects and care provided from health care professionals to cope with the child's physical social and emotional, needs (*Dean, ۲۰۱۱*).

Role of community health nurse is to help patients to cope better when they have an understanding of what is happening to them, based on their education literacy level, and interest, teaching of patients and family should focus on disease, its treatment, a risk for infection and bleeding (*Cortis & Laccy, ۲۰۱۰*).

Management of a vascular access device can be taught to most patients or family members, follow up and care for the devices may also need to be provided by nurses in an outpatient facility or by a home care agency (*Hansen, ۲۰۱۰*).

Aim of the Study

The aim of this study was to identify the health needs of children with leukemia and their families adjustment though:

١. Assess biopsychosocial needs of leukemic children.
٢. Identify the families knowledge toward leukemia.
٣. Determine the family's practice in relation to care of their leukemic children.
٤. Recognize the family's adjustment to care their children.

Research question:

١. Are the families of leukemic children aware of health needs of their children?
٢. Are the families of leukemic children able to offer health care which needed to their children?
٣. Is the community resources meet the needs of leukemic children and their families?

REVIEW

Part (I)

- ١- Definition of acute lymph plastic leukemia.
- ٢- Blood component
- ٣- Incidence and prevalence
- ٤- Possible etiological factors
- ٥- Clinical presentation
- ٦- Laboratory and diagnostic test
- ٧- Psychological impact of cancer on the child and their family
- ٨- Treatment
- ٩- Side effect of chemotherapy
- ١٠- Prognosis

Part (II)

- ١- Community health nursing role
- ٢- Management of physical care

Part (III)

- ١- Psychosocial aspects of leukemia on children and their parents
- ٢- Families adjustment toward chronic illness

Leukemia

Leukemia is the name given to a group of hematologic malignancies affecting the bone marrow and lymph nodes, in which the normal marrow elements are replaced by immature or undifferentiated blast cells (*McLaughlin et al 2008*), acute leukemia is the second most common pediatric malignancy 15% with acute lymphoblastic leukemia, constituting 80% of the cases all over the world (*Barone & Crocetti, 2000*).

Epidemiology:

Approximately, 2000 cases of childhood leukemia are diagnosed in the United States annually, all accounts for almost 70% of all cases (*Donna, 2011*).

In Egypt, childhood acute lymphoblastic leukemia was the second malignancy after Hodgkin's disease with ratio 1:1.3 respectively, pediatric acute leukemia was reported to be 1.9 (per year) (*Jamal et al., 2010*).

Acute leukemia is the most common malignancy of children less than 10 years of age the peak incidence occurs at 4 years of age, there is a male predominance for childhood acute lymphoblastic leukemia, with the incidence between 2 and 6 years of age, which consist mainly of the common form of pre B-acute leukemia (*Stiller et al., 2000*).

Acute lymphoblastic leukemia is the most common malignancy of children less than 10 years of age the peak incidence occurs at 4 years of age. There is a male predominance for childhood all, with the incidence between 2 and 6 years of age (*Jamal et al., 2010*).

Incidence and prevalence:

Leukemia is a malignant hematopoietic disease. It affects 3% from the total number of children all over the world. In Egypt, leukemia affect 36.7% from 139,1 per thousands of the total number of children aged from 0-14 years occurs frequently in male than in females children after age 1 year, the peak age of onset is between 2 and 6 years. In children the two most common forms of leukemia are acute lymphoid leukemia, and acute myelogenous leukemia (*Wong & Dockerty, 2010*).

Possible etiological factors:

The exact cause of leukemia remains unknown, but listed the possible etiological factors as the following (*Wong & Dockerty, 2010*).

I- Irradiation:

All childhood leukemia could be caused by diagnostic radiography of the mother's abdomen, while
