Effect of Self Care Guidelines on Quality of Life for Patients with Leukemia after Stem Cell Transplantation

Thesis

Submitted for Fulfillment of the Requirement of Doctorate Degree

in Nursing Science

(Medical Surgical Nursing)

By

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Introduction

Leukemia is a malignant disease of the white blood cells (WBCs) that affects all age groups. The immature WBCs generate in an explosive fashion in the bone marrow, lymph tissue, and spleen. These cells are abnormal and unable to effectively fight infection. As the disease progresses, the bone marrow continues to produce large numbers of the useless cells **(Albrecht, 2014)**.

Patient with leukemia suffers from anemia and bleeding becomes a problem as fewer and fewer platelets are manufactured. Leukemias are classified as either acute or chronic and either lymphoid or myeloid. Lymphoid leukemias affect the lymphocytes. Myeloid leukemias originate in the stem cells of the bone marrow that develop into monocytes, granulocytes, erythrocytes, and platelets **(Hopper & Williams, 2009)**.

A stem cell transplantation (SCT) is a procedure that replaces unhealthy blood-forming cells with healthy ones. The SCT is a high-risk, elective, potentially curative procedure offered to patients with hematological diseases. Also it is requiring a prolonged hospital stay and an extended recovery

period. Therefore, the biopsychosocial consequences and quality of life (QoL) for SCT recipients have to be assessed continuously become more important **(Bray, Jordens, Rowlings, Bradsock & Jan, 2015)**.

Treatment including SCT generally leads to improve survival. At the same time, hematological malignancies as well as treatment procedures are associated with impairments. The complications may affect many organs following SCT, as skin, eyes, mouth, intestine, lung and liver, as well as psychological and social wellbeing. Patients report a wide range of psychological concerns following SCT that may occur early after discharge from hospital, and continue for many months **(Hensel, Egerer, Schneeweiss & Goldsschmidt, 2012)**.

Nursing care for people with blood cancer includes providing good QoL is by educating self-care to the patients. Palliative care improves the QoL of patients and their families facing the challenges associated with a cancer diagnosis and treatment, through the early identification and thorough assessment to prevent and manage pain and other physical, psychosocial and spiritual issues (**Efficace et al., 2015)**.

The QoL is growing in importance as an outcome measure following SCT. Measurements of the QoL can provide information on the need for increased support during and after treatment. Measuring the QoL can be a prognostic indicator, which means that the patients' assessment of their QoL before treatment can predict survival **(Watson, Wraa & Osborn, 2010).**

Self-care guidelines refers to activities that enable people to deal with the impact of a long term conditions on their daily lives, dealing with the physical and psychosocial changes to give people the opportunity to improve their QoL. Self-care guidelines regarding symptoms after SCT are very important to prevent many serious problems as infection, graft-versus-host disease (GVHD), nutritional issues, nausea, fatigue, family role shifting, family distress and coping with new health status (**Mcdonald et al., 2013)**.

Significance of the study:

Leukemia is a serious disease affecting both children and adults and it requires effective management by new modalities of treatment. Annually, there is over 50,000 SCT performed worldwide according to **World Health Organization (2013).**

Nasser Institute Hospital is considered as the biggest medical center of SCT in the Middle East; approximately 280 patients were undergoing this procedure annually and more than one hundred of them had leukemia **(Nasser Institute Hospital, 2013).** Poor management and follow up after SCT can cause physical, social, psychological and financial problems so implementing self-care guidelines for those patients will lead to improve their QoL. Nurses play an important role in the assessment of patients' needs and teach them to have better outcomes, living better and enjoy a high QoL.

Aim of the Study:

This study aimed to evaluate the effect of self-care guidelines on quality of life for patients with leukemia after stem cell transplantation through the following:-

1- Assessing the quality of life dimensions for patients with leukemia after stem cell transplantation pre intervention.
2- Developing and implementing self-care guidelines for patients based on need assessment.
3- Evaluating the effect of the self-care guidelines on quality of life dimensions for patients with leukemia after stem cell transplantation.

Research Hypothesis

The current study hypothesized that:

The self-care guidelines will improve quality of life dimensions for patients with leukemia after stem cell transplantation.

Literature review

I-Anatomy and physiology of hematological system

Blood is a constantly circulating fluid providing the body with nutrition, oxygen (O2), and waste removal. Blood is mostly liquid, with numerous cells and proteins. Blood cells are divided into red blood cells (RBCs), white blood cells (WBCs) and platelets responsible for constant maintenance and immune protection of every cell type of the body. The bone marrow is the soft, spongy substance in the centre of the bone where blood cells are made **(Glenn, 2012).**

The hematopoietic system is self-renewing capable of maintaining homeostasis throughout life residing in the bone marrow. All blood cells develop from stem cells. The process of blood cell development is called hematopoiesis. In the earliest stage of blood cell development, stem cells begin to develop either along the lymphoid cell line or the myeloid cell line. In both cell lines, the stem cells become blasts, which are still immature cells. During the last stage of cell development, the blasts mature into three types of blood cells, called red bloods cells, platelets and white blood cells **(Michel, 2014).**

About 45% of total blood volume is cellular elements; it called packed cell volume (PCV). Blood cells erythrocytes or RBCs, transport O2 and carbon dioxide (CO2) in the blood. Erythrocytes contain the protein hemoglobin to which both O2 and CO2 attach. Erythrocytes are shaped like flattened donuts with a depressed center. Their flattened shape maximizes surface area for the exchange of O2 and CO2 and allows flexibility that permits their passage through narrow capillaries **(Martini, 2009).**

The WBCs or leukocytes protect the body from foreign microbes and toxins. Although all leukocytes can be found in the bloodstream, some permanently leave the bloodstream to enter tissues where they encounter microbes or toxins, while other kinds of leukocytes readily move in and out of the bloodstream. Leukocytes are classified into two groups, granulocytes and agranulocyte, based on the presence or absence of granules in the cytoplasm **(Colbert, Ankney & Lee, 2010).**

The lymphocytes attack foreign material ***(figure 1).*** The T lymphocytes kills forigen cells directely and releases lymphokines that enhance the activity of phagocytes cells. Lymphocytes are responsible for delaying the allergic reaction, rejection for foreign tissue as cellular immunity to other group

of lymphocytes. The B- lymphocytes is capable of differentiation into the plasma cells, in turn, produce antibodies called immunoglobulin's (Ig), which are protein molecules that destroy foreign material by several mechanisms, this process is known as humeral immunity **(David & Brown, 2010).**

The myeloid cell line begins with a myeloblast. As the myeloblasts reproduce and become more specialized or mature, they will eventually develop into functional blood cells, including: ***Neutrophils*** are the most numerous leukocytes, about 60-70% of the total circulating leukocytes. Neutrophils are the first line of defense against invading bacteria. ***Eosinophils*** are markedly increased in allergic diseases and increase in certain parasitic infections. ***Basophils*** are not phagocytic cells. They form and release heparin, histamine and some inflammatory mediators, which are responsible for the immediate, type hypersensitivity reaction (**Robbins, Abbas, Cotran & Nelson, 2010).**

Platelets, or thrombocytes, are not actually cells. Rather, they are granular fragments of giant cells in the bone marrow called megakaryocytes. Platelet production in the marrow is regulated in part by the hormone thrombopoietin. Platelets play an essential role in the control of bleeding. They circulate freely in the blood in an inactive state, where they nurture the

endothelium of the blood vessels, maintaining the integrity of the vessel **(Michel, 2014).**

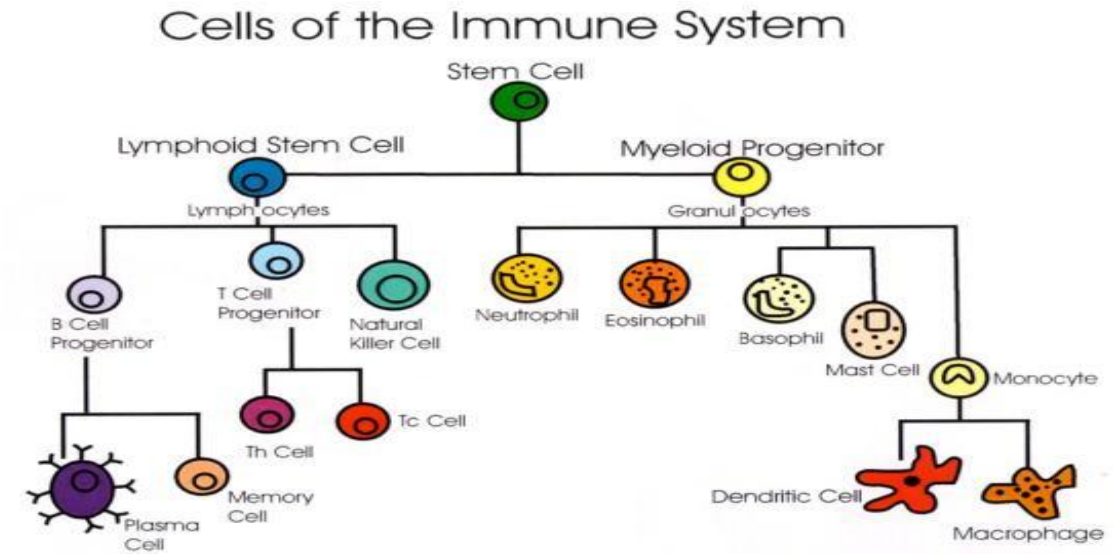

Figure (1): Types of lymphocytes, adopted from **UC Hospital (2014),** Retrieved from UC Hospital.edu.com.

II- Leukemia

Definition of leukemia:

Leukemia is a malignant disease of the WBCs that affects all age groups. The immature WBCs (blast cells) generate in an explosive fashion in the bone marrow, lymph tissue, and spleen. These cells are abnormal and unable to fight infection effectively. There are so many abnormal cells developed and dumped into the peripheral circulation that they tend to collect in the body organs and tissues, especially where circulation is sluggish. Areas especially prone to

infiltration with these immature WBCs are the oral mucosa, anus, sinuses, and lungs **(Williams & Hopper, 2013).**

As the disease progresses, the bone marrow continues to produce large numbers of the useless cells, the peripheral circulation is filled with the abnormal cells, and the bone marrow is packed with blast cells; production of most other normal cells is impossible. The patient becomes anemic because of the lack of RBCs production, and bleeding becomes a problem as fewer and fewer platelets are manufactured. However, most importantly, even though the WBCs count is very high, there are very few normal, mature, and active white cells, which are able to fight infection. Leukemia, if untreated, is usually fatal **(Pellico, 2013).**

Leukemia account for 2% of all new cases of cancer and 4% of all death from acute lymphoblastic leukemia. (**ALL**) is the most common malignancy of childhood, representing nearly one-third of all pediatric cancers. In Egypt the death rate is 4.2 per 100,000 **(WHO, 2013).**

Types of Leukemia:

Leukemias are classified as either acute or chronic and either lymphoid or myeloid. Symptoms of the acute leukemias begin very suddenly and the patient is very sick, whereas

chronic leukemias develop very slowly and patients can be surprised by the diagnosis. Lymphoid leukemias affect the lymphocytes. Myeloid leukemias originate in the stem cells of the bone marrow that develop into monocytes, granulocytes, erythrocytes, and platelets **(Smeltzer, Bare & Cheever, 2010).**

Acute leukemias: Acute lymphocytic leukemia (ALL) commonly affects children younger than age 15 and involves abnormal growth of the lymphocyte precursors (lymphoblasts). Acute myelogenous (myeloblastic) leukemia (AML) usually affects persons older than age 20 and has a poor prognosis. The patient with acute leukemia may present with sudden onset of high fever, abnormal bleeding from the mucous membranes, petechiae, ecchymoses, and easy bruising after minor trauma. Death usually results from infection **(Ignatavicius & Workman, 2010).**

Chronic leukemias: Chronic lymphocytic leukemia (CLL) predominantly affects the B and T lymphocytes and usually occurs in adults older than age 40. The CML occurs most often between the ages of 40 and 45. Chronic leukemia is usually fatal; the average survival time is 3 to 4 years after onset of the chronic phase and 3 to 6 months after onset of the acute phase **(Watson, Wraa & Osborn, 2010).**

Etiology of Leukemia:

Leukemia has unknown causes but there is some risk factors. Risk factors are including certain viruses, because remnants of viruses have been found in leukemic cells. Often there are genetic and immunological factors involved. For example, persons with Down syndrome are more likely to develop leukemia. The exposure to radiation and chemotherapy as patients who have developed leukemia after being treated for another unrelated malignancy using radiation or chemotherapy is considered as a risk factor. There is no single cause for the development of leukemias **(Timby & Smith, 2007).**

Signs and Symptoms of leukemia

Symptoms are similar in all types of leukemia and include low-grade fever caused by infection, pallor, weakness, lassitude, shortness of breath, and malaise caused by anemia. These symptoms may be present weeks or months before the appearance of other symptoms. The patient may also have dyspnea, fatigue, tachycardia, palpitations, and abdominal pain. If the leukemia has affected the central nervous system, the patient may experience confusion, headaches, and personality changes. During the acute phase the patient may exhibit high

fevers from infection. Ecchymosis or petechiae may result from thrombocytopenia (**Dewit, 2009).**

Diagnostic Tests

Although a simple CBC often points toward the diagnosis, bone marrow aspiration can show the degree of proliferation of the malignant WBCs and confirm the diagnosis of leukemia. The complete blood cell count may also show a decrease in the numbers of platelets, RBCs, and mature WBCs. A lumbar puncture helps to determine if the central nervous system is involved **(Attar, 2010).**

Complications of leukemia

Complications of leukemia include bleeding and infection, the major causes of death. The risk of bleeding correlates with the level of platelet deficiency (thrombocytopenia). The low platelet count can result in ecchymoses (bruises) and petechiae (pinpoint red or purple hemorrhagic spots on the skin). Major hemorrhages also may develop when the platelet count drops to less than 10,000/mm3. The most common sites of bleeding are gastrointestinal, pulmonary, and intracranial **(Leukemia and lymphoma society, 2014)**.