Mothers Coping Pattern Toward Their Children with Sickle Cell Anemia

Thesis

Submitted for Partial Fulfillment of Master Degree in Nursing Science
(Community Health Nursing)

By

Rahma Mohammed Mohammed
Clinical Instructor At El Mansoura Health institute
Faculty of nursing/Ain shams university

Faculty of Nursing
Ain Shams University
2018

Mothers coping pattern toward their children with sickle cell anemia

Thesis

Submitted for Partial Fulfillment of Master Degree in Nursing Science
(Community Health Nursing)

Supervisors

Assist Prof. Dr. Omaima Mohamed Esmat
Assistant Professor of Community Health Nursing
Faculty of Nursing- Ain Shams University

Assist Prof. Dr. Ferial Fouad Melika
Assistant Professor of Community Health Nursing
Faculty of Nursing- Ain Shams University

Faculty of Nursing
Ain Shams University
2018

Acknowledgement

First and foremost my thanks to **Allah** for enabling me to finish this thesis.

I wish to express my deepest gratitude to **Assist Prof Dr. Omaima Mohamed Esmat** Assistant Professor of Community Health Nursing, Faculty of Nursing, Ain Shams University, for her close supervision, continuous guidance, advice and meticulous review of the present materials.

I wish particularly to express my thanks and gratitude to **Assist Prof Dr. Ferial Fouad Melika,** Assistant Professor of Community Health Nursing, Faculty of Nursing, Ain Shams University. Not only for giving me the honor of supervision of this study but also for her greatly appreciated help, constructive advice, constant guidance and encouragement.

I wish to extend my thanks to all nursing personnel at outpatient clinic of hematology and day care hematological pediatric department in Ain Shams University Hospital for their cooperation during this study.

Last but not least many thanks to all these who contributed to achievement of this study.

Rahma Mohammed

List of Contents

List of Contents (Cont....)

List of Tables

List of Figures

List of Abbreviations

Abb.	Full term
DFO	Deferoxamine
DFP	Deferiprone
HSCT	Hematopoietic stem cell transplantation
SCA	Sickle cell anemia
SCD	Sickle cell disease

Mothers Coping Pattern Toward Their Children with Sickle Cell Anemia

Supervised by

Assist Prof/Omaima Mohamed Esmat, Assist prof/ Ferial Fouad Melika,

By

Rahma Mohammed Mohammed

Abstract

Sickle cell anemia is a genetic blood disorder where the human body produces abnormally shaped red blood cells, often in the shape of a sickle (crescent shaped). **Aim**; This study aimed at assessing mothers coping patterns toward their children with sickle cell anemia. **Research design**, **setting**; this study was conducted at outpatient clinic of hematology and day care hematological pediatric department in the Ain shams university Hospitals **sample**:130 mothers having children with sickle cell anemia were included in this study**. Tools of data collection:** Two different tools were used, ***first tool***: An interviewing questionnaire about socio demographic characteristic of mothers and their children, health needs and problems, knowledge, practices, coping pattern of mothers toward their children with sickle cell anemia, ***second tool***: Medical record of child with sickle cell anemia. **Results**: 80,8% of the total study sample achieved health needs and 73,1% of mothers having children with sickle cell anemia had cognitive health problems while 64,6% of them had social health problems.59,2%. of mothers having children with sickle cell anemia, had poor level of knowledge while, 4,6% of them had good knowledge about sickle cell anemia.67,7% of the total mothers had inadequate practices regarding their children with sickle cell anemia. While 32.3% of them had adequate practices regarding their children with sickle cell anemia.68,5% 0f mothers coping pattern adaptive. Compared to 31,5% of them were maladaptive. **Conclusion**: there was a statistical significant relation between the mothers coping pattern and mothers' total knowledge and practices about sickle cell anemia, **Recommendation**: Providing mothers with basic knowledge about health needs and problems of their children with sickle cell anemia, enhancing mother's knowledge and practices level toward care of their children with sickle cell anemia, improving mothers coping pattern and accepting responsibility of care for their children.

Key words: Coping pattern of mothers, children with sickle cell anemia.

Introduction

Anemia, as a disease state, is reflected in the reduced presence of red blood cells and lowered in hemoglobin concentration; however, its complexity relates to multiple potential pathophysiological causes ranging from genetic to environmental and inconsistent epidemiological surveillance. It is a borderless public health concern which impacts health, socio-economic status, and preferred futures for those most directly impacted. Despite the potential for intervention and treatment, anemia has remained a major cause of mortality and morbidities regionally and globally **(Mulumba and Wilson, 2015).**

Sickle cell anemia is an inherited hemolytic anemia that results from homozygous or inheritance of the sickle hemoglobin gene. It is characterized by the tendency of sickle hemoglobin to polymerize and deform the red cell to a sickle or crescent shape, thereby resulting in a characteristic vaso-occlusive phenomenon, chronic hemolysis and progressive organ damage **(Kliegman et al., 2016).**

The hemoglobin disorders are the most common clinically serious single gene disorder in the world, In

Egypt, sickle cell anemia is frequently seen in the oases where the carrier rates vary from 9 to 22% **(El Safy, 2016).**

Child affected with sickle cell anemia produce a different form of hemoglobin called hemoglobin S. Red blood cells that contain hemoglobin S have reduced life span than normal ones. They become distorted, rigid and have great difficulty passing through small blood vessels. Sickle shaped cells block blood vessels making smooth blood flow difficult to all parts of the body. Tissue damage is a serious effect of sickle cell anemia as blood tissues do not receive normal flow of blood (in turn oxygen) causing damage **(Kliegman et al., 2016).**

Other complication such as stroke, enuresis, priapism, cholelithiasis, delayed puberty, proliferative retinopathy, avascular necrosis of the hip or shoulder, and leg ulcers are introduced. **(Kaushansky et al., 2016)**

Coping is an interaction between the person's internal resources and external environmental demands. It includes attempts to reduce the perceived discrepancy between situational demands and personal resources **(Markofa and Nikitskya, 2017).**

The community health nurse provides appropriate multidisciplinary care for mothers and their children with

sickle cell anemia, such as educating mothers about prophylaxis, and immunizations, including pneumococcal vaccines. Education about the need for urgent medical evaluation for treatment of febrile illness, acute splenic sequestration, aplastic crisis, and acute chest syndrome is critical. Education about splenic sequestration includes the need to seek medical attention immediately if the child is pale and listless and instruction about abdominal palpation for determining spleen size. Recognition and appropriate management of dactylitis and other painful events should be reviewed **(Elhosany, 2011).**

The ultimate goal of community health nurse is to enable mothers to functionally cope with the child's complex chronic illness and enhance the child's potential for successful transition to adulthood **(Kaushansky et al., 2016).**