

Quality of Life for Children with β -Thalassemia

Thesis

Submitted For Partial Fulfillment of the

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(Pediatric Nursing)

Faculty of Nursing- Ain Shams University

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قَالُوا سُبْحَانَكَ لَا عِلْمَ لَنَا
إِلَّا مَا عَلَّمْتَنَا إِنَّكَ أَنْتَ
الْعَلِيمُ الْحَكِيمُ

صدق الله العظيم

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my gratitude goes to all patients and their parents wishing them a very rapid and complete permanent recovery.



Mahmoud hassan

Dedicated To:

My Father.....

My Mother....

My Brothers &

My Sisters

*For their great help, encouragement, love
and continuous support*

Abstract

Background: The assessment of quality of life (QOL) in children, especially in those with chronic illness such as thalassemia, is important as nursing assessment in that it focuses on the children's own views of their well-being and other aspects of life. The aim of the present study was to: assess the quality of life of children with β thalassemia. **Settings :** The present study was carried at Al-Amira Rahma Hospital and Services Hospital Royal in Jordan. These places were selected because it is well known established places that provide care for such children and also due to its high flow rate of attendance. **Subjects:** A purposive sample composed of all available children (100) with β thalassemia in the previously mentioned settings accompanied with their mothers, under inclusion criteria (children aged from 6 to 15 years and confirmed diagnosis β thalassemia). **Tool of data collection:** Data were collected by using a pre-designed questionnaire sheet and QOL scale, medical record. **Results:** The present study revealed that, 87.0% of the studied children have satisfactory knowledge about thalassemia. **Conclusion:** The study concluded that there was a statistical significant difference between duration of illness of the studied children's and their QOL domain of physical well-being. **Recommendations:** The study recommended the application program for children have thalassemia and their mother about prevention and management of their health problem .

Keyword: children, β thalassemia, QOL.

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List of Abbreviations

AFT	Amniotic Fluid Test
<i>APA</i>	<i>American Pregnancy Association</i>
BM	Bone Marrow
BMT	Bone Marrow Transplantation
CBC	Complete Blood Counts
CT	Computed Tomography
<i>DFO</i>	<i>Desferoxamine:</i>
DFX	Deferasirox (ICL670, Exjade)
DNA	Deoxyribonucleic Acid
ECG	Electrocardiography
EMR	Eastern Mediterranean
<i>GHR</i>	<i>Genetics Home References</i>
Hb	Hemoglobin

HbA	Hemoglobin A
Hb-D- β -thalassemia	Hemoglobin D- β - thalassemia
Hb-S- β -thalassemia	Sickle Cell- β thalassemia
HRQOL	Health Related Quality of Life
HSCT	Hematopoietic Stem Cell Transplantation
ICT	Iron Chelation Therapy
IQ	Intelligence Quotient
IRPS	Iron-Regularity Proteins
MCV	Mean Corpuscular Volume
NTBI	Non-Transferrin Bound Iron
OOS	Osteopenia Osteoporosis Syndrome
PGD	Preimplantation Genetic Disease Diagnosis
QOL	Quality of Life
QOL	Quality of Life
RBC	Red Blood Cell
RBCs	Red Blood Cells

RDW	Red Cell Distribution Width
TFC	Thalessemia Foundation of Canada
<i>WHO</i>	World Health Organization
α	Alpha
β	Beta
β 2 –MG	β 2 –Microglobulin
β TI	β -Thalassemia Intermedia
β TM	β -Thalassemia Major