

Introduction

Benign hematological disorders including Hemoglobinopathies and coagulation disorders are common in the pediatric population with different presentations.

Thalassemia is disorder resulting from globin chain synthesis impairment through the mutation or deletion of globin genes.

Sickle cell disease (SCD) is hematologic disorder caused by mutation that leads to the formation of abnormal hemoglobin S which cause sickling of erythrocytes.

Hemophilia is characterized by spontaneous and post-traumatic bleeding events into the joints, muscles, and soft tissues, which can lead to disability.

Chronic illness significantly impacts millions of families and siblings each year. The impact of having an illness in the family extends across various aspects of life, including financial, physical, emotional, social, behavioral, and personal domains.

Health-related quality of life, or HRQOL, is likely to be a crucial factor when deciding how best to treat individual patients and how best to allocate health care resources for chronic disorders which there is no known cure and treatment may be extended. Research on child health services has acknowledged HRQOL as a significant health consequence.

Aim of the work

The aim of the present study was to assess and compare the quality of life of children with three named chronic benign hematological illnesses (thalassemia, sickle cell anemia, and hemophilia), to measure and compare the impact of these chronic benign hematological illnesses on the parent(s) of the studied children and To assess the possible risk factors affecting the quality of life of the studied children and the impact on their families.

Patients and Methods

This cross-sectional study included all children aged 2-12 years, with the named chronic benign hematological illnesses (thalassemia, sickle cell anemia, and hemophilia) and their parents. All children were followed up at the hematology clinic of Alexandria University Children's Hospital for at least six months duration. 115 children were included in this study and categorized according to their diagnosis as follows: Group A: thalassemia (n =71), Group B: sickle cell anemia (n=14), Group C: hemophilia (n=30).

Interview with the parents of the selected children included the following questionnaire:

- Demographic data including; name, sex, age, family history included marital status, family structure, residency, consanguinity, similar condition among siblings.
- The Arabic form of Pediatric Quality of Life Inventory™ 4.0 (PedsQL™) generic core scale (parent report). Pediatric Quality of Life Inventory™ (PedsQL™) version 4.0 for age groups 2–4 years, 5–7 years and 8–12 years will be used.
- The Arabic form of Pediatric Quality of Life Inventory™ 4.0 (PedsQL™) generic core scale (Self- report) for children from (8-12) years
- The Arabic form of Pediatric PedsQL™ Family Impact Module, (PedsQL™ FIM) version 2.0.

Results

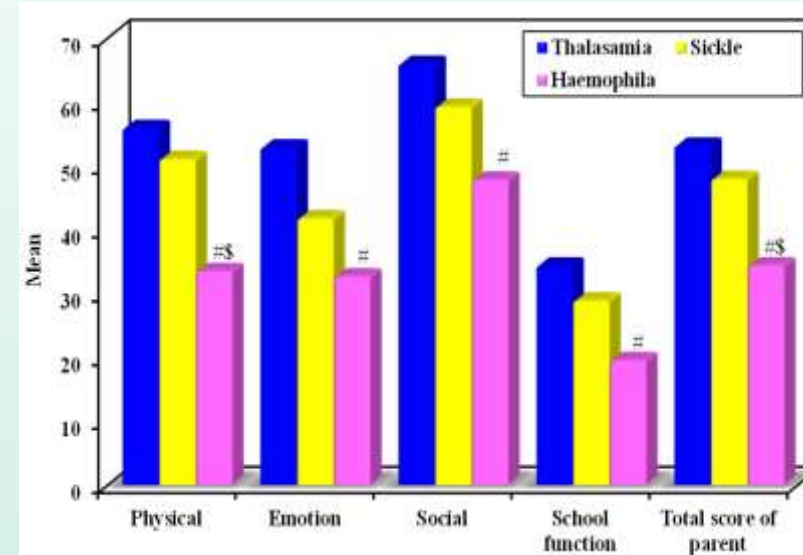


Figure 1:

Comparison between the different studied groups according to parent report of 4. 0 generic core questionnaire parameters

#: between thalasamia and haemophila
\$: between sickle and haemophilia

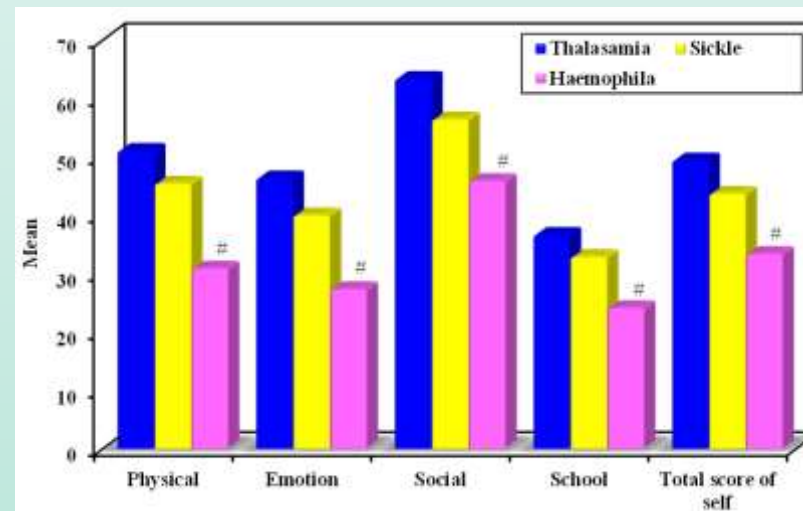


Figure 2:

Comparison between the different studied groups according to self report of 4. 0 generic core questionnaire.

#: between thalasamia and haemophila

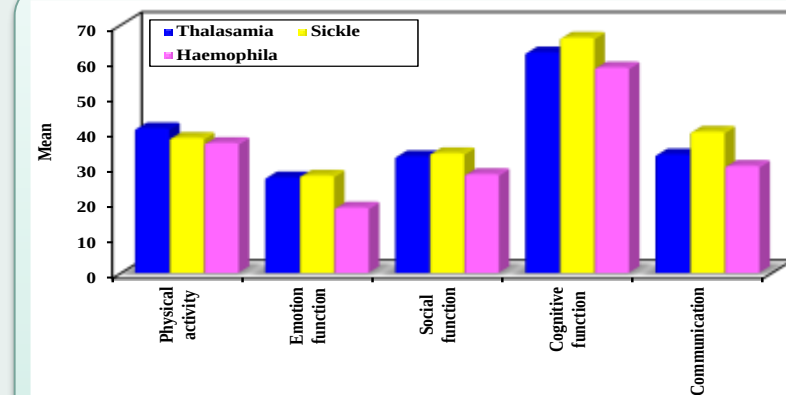
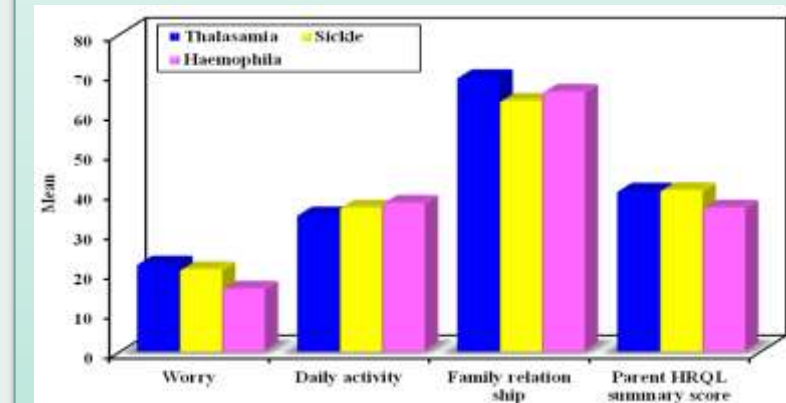


Figure 3:

Comparison between the different studied groups according to PedsQL TM 2. 0 family impact module questionnaire



Conclusion

In the current study, according to PedsQL TM 2. 0 Family Impact Module questionnaire had applied on different studied groups, there is no significant difference on the quality of life between 3 diseases but the mean Parent HRQL summary score hemophilia has lowest score due to both psychosocial and financial challenge

In the current study, according to Pediatric Quality of Life Inventory™ 4.0 (PedsQL™) generic core scale parent parameters and self-parameters had applied on 3 studied groups the school function score has lowest score due to Frequent school absence for hospital visits and lack of both mental and physical energies when achieving academic educational activities.