Health-Related Quality of Life in Children with Immune Thrombocytopenic Purpura And Their Parents

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List of Abbreviations

APLA : anti-phospholipid antibodies

APS : anti phospholipid syndrome

BMI : Body mass index

CBC : Complete blood count

CLL : chronic lymphocytic leukemia

CMV : cytomegalovirus

GPIb : glycoprotein Ib

H, pylori : Helicobacter pylori

Hb : Hemoglobin concentration

HCV : Hepatitis C virus

HIT : Heparin-induced thrombocytopenia

HIV :human immune supressive virus

HRQOL : Health-Related Quality of Life

Ht : Height

***ICC** : Interclass correlation*

ICH : intracerebral hemorrhage

IgG : immunoglobulin G

ITP : Idiopathic thrombocytopenic purpura

IVIg : intra venous immunoglobulin

KIT : Kids' ITP Tools

MMR :measles,mumps,rubella

MPV :mean platelet volume

NAI : non-accidental injury

PAIgG : platelet-associated immunoglobulin G

PAQ : Patient Assessment Questionnaire

PDW : platelet size deviation width

P-LCR : platelet-to-large-cell ratio

SF-36 : Short-Form 36 questionnaire

SLE : Systemic lupus erythematosus

SD *: standard deviation*

S.S *: summary score*

TPO : thrombopoietin

WBC : White blood count

WT : Weight

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قَالُوا سُبْحَانَكَ
لَا عِلْمَ لَنَا
إِلَّا مَا عَلَّمْتَنَا
إِنَّكَ أَنْتَ
الْعَلِيمُ الْحَكِيمُ
صدق الله العظيم
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Abstract

Objectives: measuring Health Related Quality of Life of an Egyptian Sample of children with immune thrombocytopenic purpura in relation to disease parameters by a cross-culturally valid tool. **Methods.** Kid's ITP Tool was translated and validated to measure HRQoL of 80 ITP children and their parents. They were recruited from Haematology Clinic, Ain Shams University Children's Hospital in the period from May 2009 to December 2010. **Results:** Parent report mean scores were significantly lower than child/proxy report mean scores especially among those with chronic ITP. There was a positive correlation between child/proxy scores and parent scores. Patients with acute ITP had significantly lower mean scores than those with chronic ITP regarding both child/proxy report scores and parent report scores specifically those with acute non-resolved course. Longer duration of illness was correlated with higher child/proxy report scores. Both child/proxy report scores and parent report mean scores were significantly lower among patients with higher severity of bleeding. A negative correlations were found between the severity of bleeding and both child/proxy scores and parents scores. Platelet count was positively correlated to parent report scores. Regression analysis revealed that only parent report scores had significant effect on child/proxy report scores. Meanwhile the severity of bleeding had the highest significant effect on parent score followed by child/proxy report scores.

Conclusion: A causal linkage of both the severity of symptoms of ITP and platelet count with the quality of life in children with ITP and their parents was found.

Introduction

Idiopathic or immune thrombocytopenic purpura (ITP) is a bleeding disorder_characterized by too few platelets in the blood. This is because platelets are being destroyed by the immune system. Idiopathic means the exact cause of the disease is unknown **(Kuhne et al., 2001)**.

It is one of the most common haematologic disorders affecting children, with an incidence of 4 to 5 cases per 100 000 children per year. Although the sudden onset of bleeding is alarming to parents and primary physicians, affected children generally have a good prognosis **(Cines and Blanchette, 2002).**

Both the natural course of ITP and the risk of life threatening bleeding are unpredictable, also the clinical outcome, that is acute or chronic ITP is influenced by drug treatment is unclear **(Lilleyman, 2000).**

ITP may follow acute or chronic course, acute ITP in children often goes away on its own within a few weeks or months and doesn't return. In 80 percent of children who have ITP, the platelet count returns to normal within 6 to 12 months. Treatment may not be needed. A small number of children, about 5 percent, whose ITP doesn't go away on its own may need to have further medical or surgical treatment. Chronic ITP will vary with each individual and can last many years. Even people who have severe forms of chronic ITP can live for

decades. Most people with chronic ITP are able at some point to stop treatment and keep a safe platelet count **(Kuhne et al., 2001).**

The most frequently reported outcome in prior studies of childhood ITP is platelet count. This is often viewed as a surrogate marker of hemorrhagic risk, for minor bleeding as well as hemorrhage in critical sites, such as the central nervous system **(Buchanan and Adix, 2001)**.

It has recently been recognized, however, that other outcomes in ITP are important, including health-related quality of life, adverse effects of treatment, and the cost of therapy **(Klaassen et al., 2007).**

Considerations involving the health-related quality of life of the child with immune thrombocytopenic purpura and that of the child's parents have the potential to influence treatment decisions. As there is no established standard approach to the treatment of ITP, management decisions can be modified based on individual child and family needs **(Barnard et al., 2003).**

Aim of work

The aim of this study is to measure HRQoL in a sample of Egyptian children with ITP in relation to disease parameters (course and duration of the disease, severity of bleeding, type of treatment and its side effects) using the KIT after being cross-culturally translated into Arabic language.