

## Improving Quality of Life of Mothers and their Children with Immune Thrombocytopenia

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### Abstract:

**Background:** Immune thrombocytopenia is an autoimmune disease characterized by a low platelet count (less than  $100 \times 10^9 /L$ ) and pediatric patients may develop bruising or mucosal bleeding. The concept of health-related quality of life was first proposed decades ago and has been successfully applied in a variety of contexts. **Aim:** This study aimed to improve the quality of life of mothers and their children with immune thrombocytopenia. **Design:** A quasi-experimental design was utilized. **Setting:** The study was conducted at Benha Specialized Pediatric Hospital which affiliated to secretariat of specialized medical centers (in outpatient clinics and hematology ward) at Benha city. **Sample:** A purposive sample of children with Immune thrombocytopenia aged from 2 to less than 18 years and their mothers were recruited. **Tools of data collection:** Four tools were used to conduct the study. **Tool (I):** Structured Interviewing Questionnaire which included 2 parts; **Part (1)** Personal characteristic of studied mothers. **Part (2):** Mother's knowledge regarding ITP. **Tool (II):** Medical Data Sheet which included 2 parts; **Part (1):** Personal data of the studied children. **Part (2):** Previous and current medical history. **Tool (III):** Mothers' reported practice to assess mothers' care given to their children with immune thrombocytopenia which include nose bleeding, wound care, bathing, teeth brushing, mouth care, skin care and hair care and administration of oral medications. **Tool (IV):** Scale of pediatric quality of life (Kids ITP tools) to assess the quality of life of children with Immune thrombocytopenia. **Results:** Less than quarter (22.0%) of the studied mothers had satisfactory level of reported practice in pre-guidelines phase, while (86.0% & 80.0%) of them had satisfactory level of reported practice toward improving the quality of life of their children with thrombocytopenia in post- guidelines and at follow-up phase. Mean child scores of PedsQL was  $48.18 \pm 14.93$  pre guidelines and  $60.32 \pm 11.22$  post guidelines phase. Less than half (40.0%) of the studied children had positive quality of life in pre-guidelines phase, while (68.0% & 64%) of them had positive quality of life in post-guidelines phase and follow-up phase. **Conclusion:** The designed guidelines succeed to improved mother's knowledge and reported practice regarding ITP and children's quality of life. **Recommendations:** More researches are required for training of mothers, about the proper care of children with immune thrombocytopenia and raising their awareness about the nature of disease and right practices should be done in daily different situations.

**Keywords:** Children, Immune thrombocytopenia (ITP), Quality of life (QoL).

### Introduction

Immune thrombocytopenia (ITP) is a disorder that can lead to mild or excessive bruising and bleeding. The bleeding results from unusually low levels of platelets cells

that help blood clot. ITP is a disorder where the immune system damages platelets, which are blood cells that cause blood clots to develop. Mild bruising and bleeding, which may be seen as purple patches of skin, mucous membranes, and organ outer linings

may be seen as a result of the low platelet. (Gruhn et al., 2021).

Immune thrombocytopenia (ITP) of childhood is characterized by isolated thrombocytopenia (platelet count <100,000/microL with normal white blood cell count and hemoglobin). ITP was previously known as idiopathic thrombocytopenic purpura or immune thrombocytopenic purpura (Hinson & Saxonhouse, 2019).

Immune thrombocytopenia was divided into three categories based on how long it had been present: chronic (more than 12 months), persistent (>3 months), and recently diagnosed (0–3 months). It can be also classified according to the cause as idiopathic thrombocytopenia increases the risk of a life-threatening hemorrhage due to antibody-mediated platelet destruction and platelet production impairment (Saettini et al., 2021).

Thrombocytopenia signs and symptoms may include blood in the urine or stools, prolonged bleeding from cuts include bleeding from the gums or nose, mild to severe bruising (purpura), superficial bleeding into the skin that appears as a rash of tiny reddish-purple spots, typically on the lower legs, lethargy, and an enlarged spleen. (Park et al., 2021).

Quality of Life (QoL) is the level to which an individual is healthy, comfortable, and able to engage in or enjoy life events. QoL is considered in terms of how a certain illness affects patient on an individual level. Experience sampling studies measure quality of life as the patient's ability to engage in normal life activities since life quality strongly related to well – being without suffering from sickness and treatment. Measures of QoL should take in to account

attributes of physical, psychological and financial well- being. Studies of health-related quality of life (HRQoL) in children with ITP have revealed significant disease burden in addition to the physical manifestations, including anxiety related to the risk of bleeding, sadness, and negative effects on daily activities. (Grace et al., 2020).

The nurse is crucial in the care of ITP children because she makes parents and other family members more aware of the disease and the importance of supervision playthings. Children should be taught self-defense skills to stop bleeding. When it comes to everyday objects that might hurt children, such as sharp objects and household lime, she should make sure that homes, playgrounds, and schools are safe. The nurses are crucial in helping mothers understand immune thrombocytopenia. (Khair, 2021)

#### **Significance of the study:**

Children with immune thrombocytopenia (ITP) typically bleed little and have a low platelet count. Serious bleeding affects 3% of children, and 1 to 5 cerebral hemorrhage per 1,000 children are thought to occur. Life-threatening bleeding is extremely uncommon. Studying health-related quality of life (HRQoL) and how the illness affected their parents was necessary because, despite the low risk of serious bleeding, children and parents worry, restricting activities and negatively affecting the child's quality of life (Tantawy et al., 2020).

Many children with very low platelet counts do not bleed, so more clinically relevant outcome measures are necessary. Despite the benign nature of chronic ITP, families face a financial burden from treatment and healthcare costs, especially those who have limited resources. Children must deal with some physical activity

limitations, disruptions in their academic and social lives due to hospitalization, and emotional and psychological changes brought on by the illness' recurrence. For HRQoL to be used as an outcome measure in international multicenter clinical trials, the measure needs to be psychometrically strong across various countries (**Shimano et al., 2021**). So that, this study aimed to improve the quality of life of mothers and their children with immunological thrombocytopenia.

### **Aim of the study:**

This study aimed to improve quality of life of mothers and their children with immune thrombocytopenia (ITP).

### **Research Hypothesis:**

- The designed guidelines will improve mothers' knowledge and reported practice regarding ITP
- The guidelines given to mothers will improve quality of life of mothers and their children.

### **Research design:**

To fulfill the aim of the study a quasi-experimental design (pre-posttest- after 3month follow up test) was used

### **Research setting:**

This study was conducted at Benha Specialized Pediatric Hospital which affiliated to secretariat of specialized medical centers in hematology department which sited in the fourth floor and composed of two rooms each room contain four beds with total 8 beds and outpatient hematology clinic which located in the first floor and composed of one room.

### **Research sampling:**

The study included a purposive sample of 50 mothers and their children who had Immune Thrombocytopenia (ITP) during the data collection period. The children who met

the prerequisite inclusion criteria and their mothers who agreed to take part in the study were recruited.

### **Inclusion criteria**

- Children with ITP from both gender.
- Age of children from 2 to less than 18 years old.
- Free from autoimmune diseases.

### **Tools for data collection:**

Four tools were utilized for data collection:

#### **Tool I: A structured Interviewing Questionnaire:**

This tool was designed and developed by the researcher under direction of supervisors in a simple Arabic language after reviewing scientific and relevant literatures to assess mothers' knowledge regarding ITP, it consisted of two main parts: -

**Part (1):** Personal characteristics of the studied mothers consisted of (5) questions about: age, educational level, occupation, residence and kinship between parents.

#### **Part (2):**

Mothers' knowledge regarding immune thrombocytopenia (ITP) based on (**Schifferli et al., 2021**). It composed of seven (7) multiple choice questions about: definition (1), duration (2), clinical manifestations (1), complications (1), normal platelet count complications (1), and diagnosis (1). **Additionally**, 10 multiple choice questions regarding their knowledge about management of ITP such as; bleeding (2), wounds (1), daily activities (2), kind of food (1), bathing the child (1), teeth brushing (1), oral care (1) and medications (1).

#### **Scoring system of mothers' knowledge**

The model key answers were used to compare the responses from the studied mothers, Answers that were completely

correct scored (2), incomplete correct answer scored (1) and incorrect or don't know answer scored (0). Mothers' total knowledge score is categorized into:

- Adequate: mothers' knowledge score  $\geq 60\%$ .
- Inadequate: mothers' knowledge score  $< 60\%$

#### **Tool II: Medical Data Sheet of children.**

This tool consisted of two parts:

**Part (1):** Personal characteristics of the studied children it composed of (4) questions about: age, education, gender and child rank.

**Part (2):** Previous and current medical data of children with immune thrombocytopenia (ITP) it composed of (13) questions about; viral infection, child past and current complain, heredity, medications, mothers' chronic disease, family history and mother's health problems during pregnancy.

#### **Tool III: Mothers' Reported Practice**

It was adopted from **Perry et al., (2017)** and **Matos et al., (2018)** to assess mothers' reported care given to their children with immune thrombocytopenia (ITP). It composed of (8) procedures, with total steps (82), which includes; nose bleeding(epistaxis) (10 steps), wound care (14 steps), bathing the child (9 steps), teeth brushing (12 steps), oral care (8 steps), skin care (9 steps) and hair care (9 steps) and administration of oral medications (11 steps).

#### **Scoring system for mothers reported practice**

Score (1) was provided for the correct step, and score (0) was given for a step that was incorrect or not done, according to the scoring system for mother's practices. The total score of the practices that mothers reported was divided into:

- Satisfactory:  $\geq 60\%$  of total mothers' reported practice score.

- Unsatisfactory:  $< 60\%$  of total mothers' reported practice score.

#### **Tool IV: Scale of pediatric quality of life - kids ITP (KIT)**

This scale was adapted from **Trotter, P., and Hill, Q. A. (2018)** and modified by the researcher to suit this study. It consisting of two parts

**Part (1):** Pediatric quality of life scale which consisting of seven (7) main items with 37 sub items as follow:

- Daily activities (9 items)
- School activities (4 items)
- Movement and balance (5 items)
- Pain (4 items)
- Fatigue (4 items)
- Eating activities (5 items)
- Speech and communications (6 items)

**Part (2):** Kids ITP sheet which composed of eighteen (18) questions about: anxiety, anger, fear, depression or sadness, activity, energy and fatigue, ability of play, pain, physical performance, sleep, physical condition, school, academic achievement, daily tasks, reset.

#### **Scoring system for Scale of pediatric quality of life -kids ITP (KIT)**

The score for each response of Pediatric quality of life scale as the following: yes, response scored (2), sometimes response scored (1) and no response scored (0).

#### **The total scoring of Pediatric quality of life scale**

- Positive Pediatric quality of life 80% of total score
- Fair Pediatric quality of life 50% to less than 80% of total score.
- Negative Pediatric quality of life less than 50% of total score.

#### **Content validity and reliability of the tool:**

The study tools were revised by three Pediatric Nursing experts from Benha

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University (one professor and two assistant professors). The tools were examined by experts for clarity, relevance, simplicity, and applicability; as a result, modest improvements were made. This phase was designed to test the content of the designed tools through eliciting opinions of the jury group regarding agreement upon the proposed guidelines. Responses to the standards statement and its criteria from the jury group members, including comments and indications of agreement or disagreement. Testing the reliability of the proposed tools (I& II&III) was done by using the Cronbach's Alpha test. Reliability of knowledge equal 0.81 ( $\alpha =0.81$ ), reliability for practice equal 0.76. ( $\alpha =0.76$ )

### **Ethical considerations:**

An ethical approval was taken from the ethical committee of Faculty of Nursing, Benha University. Before including any mothers in the study, the researcher explained to them the purpose, design, and anticipated results. They were asked to give their moms' oral consent prior to taking part in the study. The study subjects' confidentiality and anonymity were protected. Mothers were made aware that the information will only be utilized for study. Mothers were free to leave the study whenever they wanted.

### **Pilot study:**

The pilot study was conducted on May 2020 on 10% of the studied subjects (5) of mothers and their children with Immune thrombocytopenia to assess the validity and applicability of the tools and determine how much time would be needed to complete the questionnaire. The tools were modified according to the result of the pilot study and expert's opinion and the pilot number of

mothers and children was included in the study sample.

### **Field work:**

The data was collected from mothers who attended with their ITP children in the previously mentioned setting (inpatient and outpatient clinic) through the interview with them. The data gathering procedure took place during 9 months' period. (Six months for phases of the study and three months for follow up). The study was carried out from the beginning of July 2020 to the end of March 2021. The researcher was available at each study setting two days/ week from 9.00 AM. to 2:00 PM to collect data utilizing the preceding tools.

The following phases of the study were completed:

#### **a- Assessment phase**

Prior to collecting any data, the researchers conducted interviews with the each mother individually, during which they introduced themselves, clarified the nature of the study, and got their consent to participate. The interview took between 30 and 40 minutes to complete depending on the mothers' responses. The researcher helped mothers who couldn't complete the questionnaire by explaining, and the researcher gave their children little rewards to keep them motivated during the gathering stage. Each child with Immune thrombocytopenia (ITP) was observed by the researcher to observe signs of the disease. The personal and medical data were collected from mothers and medical files within nearly 10- 15 minutes and each child's scales were filled out in a time frame of 20 to 25 minutes, assuring complete privacy and confidentiality.

#### **b- Planning Phase**

Afterward determining the needed knowledge and practices, the researcher

designed guidelines regarding knowledge and practices for mothers for improving the quality of life of their children with ITP. The guidelines were used in simple Arabic language and several illustrated colored pictures to facilitate mothers understanding.

### **c- Implementation phase**

The questionnaire sheets were distributed to each mother individually to evaluate each mother's understanding and experience with immune thrombocytopenia through a pretest, following the pre-test, the researcher gave the mothers an explanation of the designed guidelines and provided information depending on their needs for knowledge and practices. They were informed they may task about anything at any time. The guidelines were given to the mothers to follow it as wanted. The researcher explained the guidelines taking into account the use of Arabic language that suits the mothers' educational level. The researcher continued to reinforce the knowledge she had acquired, responding to any questions and providing feedback.

#### **Sessions of implementation:**

**Six sessions, divided as follows, were used to complete the implementation sessions: two knowledge-building sessions and four practice sessions.** Each session began with an overview of the previous one and its goals. Consider utilizing Arabic that appropriates the mothers' educational background when using the language. In this study, motivation and reinforcement were employed during sessions to increase motivation for sharing. The session lasted 30 to 45 minutes, and 4-6 mothers were informed of each group's performance and subsequent re-demonstration. Role playing, discussion in groups, and handouts were all used by the researcher as teaching techniques during knowledge sessions. **Session 1:**

#### **Designed guidelines orientation and overview on ITP**

The aim of designed guidelines orientation is to orient mothers about the importance of following the guidelines plan and expectation from each session was discussed and provide mothers with information to raise their knowledge about ITP as definition, causes, types, diagnosis, signs and symptoms and complications.

#### **Session 2: knowledge regarding appropriate management of ITP.**

This session aimed to improve mother's knowledge regarding management of the ITP like nutrition, safety and daily activity.

#### **Session 3: Demonstration of oral medication practice**

The aim of this session is to improve mothers' practice and enable them to perform the correct way for giving oral medication.

#### **Session 4: Demonstration of practices (wound care and control of epistaxis)**

The aim of this session is to improve mother's practice regard children with ITP and enable them to perform the correct way to care of wound and to control of nose bleeding for their children at home.

#### **Session 5: Demonstration of practices (skin care and bathing)**

The aim of this session is to improve mother's practice regard children with ITP and enable them to perform skin care and bathing in the correct way for their children at home.

#### **Session 6: Demonstration of practices (tooth brushing and oral care)**

The aim of this session is to improve mother's practice regard children with ITP and help them to protect and care of their

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teeth without fair being hurt and perform oral care for their children at home.

### **d- Evaluation Phase:**

The researchers asked mothers to complete a post-test utilizing the same format of data collection tools during the final session.

### **e- Follow up:**

Follow up test conducted after 3 months. The researcher connected with mothers via telephone. The researcher asked the mothers to apply post-test by using the same set of data collection tools data collection tools

### **Statistical analysis:**

Data collected were organized, tabulated and statistically analyzed using Statistical Package for Social Science (SPSS version 21), running on electronic computer. For qualitative descriptive data, frequencies and percentage distribution were employed, while for relationship tests, the chi-square coefficient ( $X^2$ ) was utilized, and for quantitative data, the mean and standard deviation were used. Correlation analysis was performed using the Pearson correlation coefficient ( $r$ ), and the level of significance was determined.

The observation difference of statistically significance variable and associations were considered as the following: (p-value)

- Highly statistically significant difference (HS)  $p < 0.001$
- Statistically significant difference (S)  $p < 0.05$
- No statistically significant difference (NS)  $p > 0.05$

### **Results:**

**Table (1):** reveals that the main age of studied mothers was  $33.68 \pm 7.22$  years. More than two fifth of studied mothers (44%) were

between 30>40 years. The minority of them (4%) were under 20 years. As regards to educational qualifications. more than one third (40%) of mothers had secondary education. And the minority of them (2%) Neither read nor write. Also this table illustrates that about two third of studied mothers (64%) were from rural areas. Regarding kinship between parents the table notes that there was no kinship in near to two third (62%) of studied sample.

**Table (2):** Illustrates that, more than half (54%) of the studied children were between 4>8 years. with mean age  $7.22 \pm 3.52$  years. The table additionally reveals that more than one third (38.0%) of them were males. Regarding to educational stage more than half of children age (54%) were in preschool stage. The minority of children (2%) were in secondary stage.

**Figure (1):** Reveals that, more than one quarter (28%) of studied mothers had adequate level of knowledge in pre-guidelines phase, more than three quarters (88.0% and 82.0%) of them had adequate level of knowledge in post-guidelines and follow-up phases respectively.

**Figure (2)** Reflects that, less than quarter (22.0%) of the studied mothers had satisfactory level of practice in pre-guidelines phase, the majority (86.0%) of the studied mothers had satisfactory level of practice in post-guidelines and more than three quarters (80.0%) of them had satisfactory level of practice toward improving the quality of life of their children with thrombocytopenia at follow-up phase.

**Figure (3)** Reflects that, less than half (40.0%) of the studied children had positive quality of life in pre-guidelines phase, more than two thirds (68.0%) of the studied

children had positive quality of life in post-guidelines phase and less than two thirds (64%) of them had had positive quality of life at follow-up phase.

**Table (3)** Clarifies that, there was a highly statistically significant relation between total knowledge score of the studied mothers and their Personal characteristics at pre-guidelines phase ( $P < 0.001$ ) compared to no statistically significant relation at post-guidelines phase ( $P > 0.05$ ). Moreover, there was no a statistically significant relation between studied mothers' total knowledge and Personal characteristics at follow-up phases ( $P > 0.05$ ).

**Table (4)** Clarifies that, there was a highly statistically significant relation between total reported practice score of the studied mothers and their Personal characteristics at pre-guidelines phase ( $P < 0.001$ ) compared to no statistically significant relation at post-guidelines phase ( $P > 0.05$ ). Moreover, there was no a statistically significant relation between studied mothers' total reported practices and Personal characteristics at follow-up phases ( $P > 0.05$ ).

**Table (5)** Clarifies that, there was a highly positive statistical correlation between total knowledge and total reported practice scores at pre-guidelines, post-guidelines and follow-up phase ( $p < 0.001$ ).



**Table (1): Distribution of the studied mothers according to their personal data (n=50).**

Personal data	No.	%
<b>Age (years)</b>		
<20	2	4.0
20>30	12	24.0
30>40	22	44.0
≥40	14	28.0
<b>Mean ±SD</b>	33.68±7.22	
<b>Educational qualification</b>		
Neither read nor write	2	4.0
Primary education	4	8.0
Preparatory education	8	16.0
Secondary education	20	40.0
University education	16	32.0
<b>Occupation</b>		
Working	17	34.0
House wife	33	66.0
<b>Residence</b>		
Rural	32	64.0
Urban	18	36.0
<b>Kinship between the father and the mother</b>		
Yes	19	38.0
No	31	62.0

**Table (2): Distribution of the studied children according to their personal data (n=50).**

personal data	No	%
<b>Age (years)</b>		
2>4	11	22.0
4>8	27	54.0
8>12	8	16.0
12>18	4	8.0
<b>Mean ±SD</b>	7.22±3.52	
<b>Educational stage</b>		
Pre-school	27	54.0
Primary stage	15	30.0
Preparatory stage	7	14.0
Secondary stage	1	2.0
<b>Child's gender</b>		
Male	31	62.0
Female	19	38.0
<b>Arranging the child among the family</b>		
First	4	8.0
Second	14	28.0
Third	20	40.0
Fourth	12	24.0

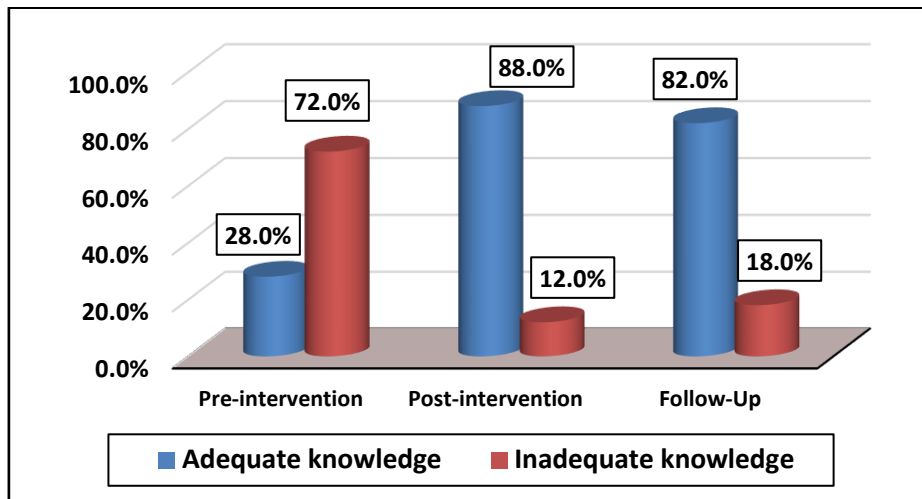


Figure (1): Percentage distribution of studied mothers' according to their total knowledge regarding thrombocytopenia and its management at pre guidelines, post guidelines and follow-up phases (n = 50)

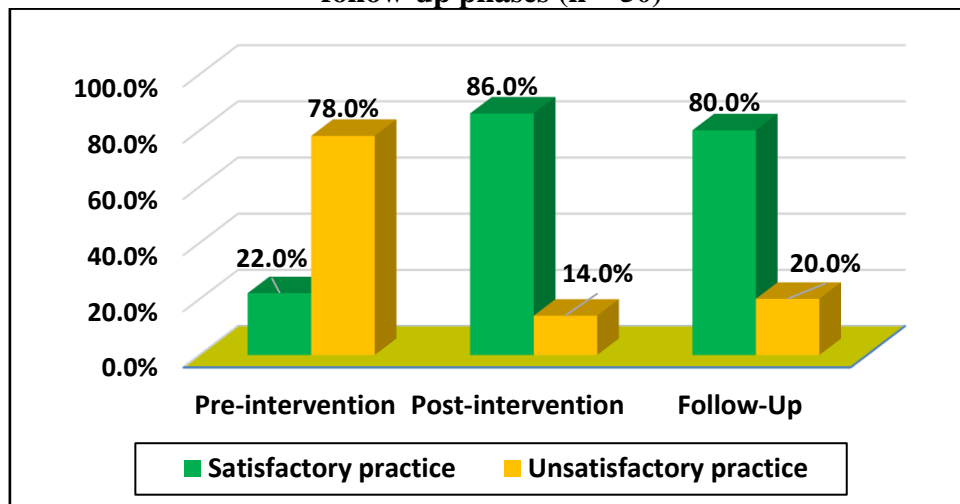


Figure (2): Percentage distribution of studied mothers' practice to improve the quality of life of their children with thrombocytopenia at pre guidelines, post guidelines and follow-up phases (n = 50)

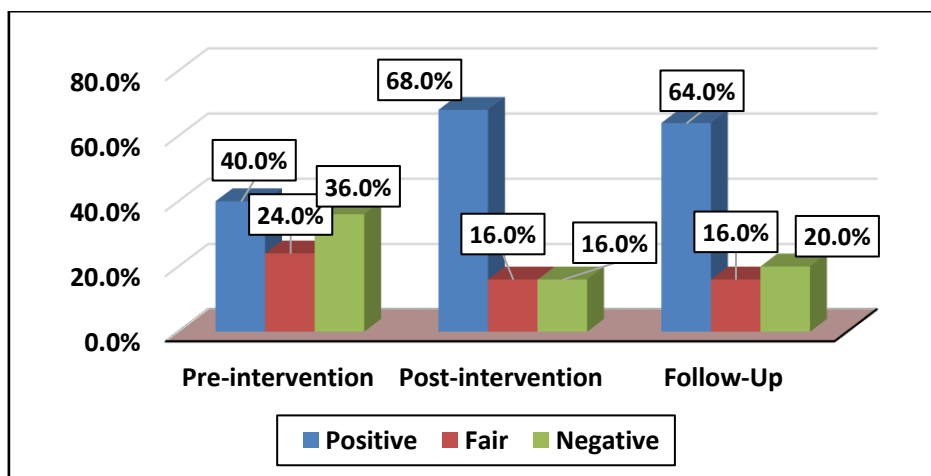


Figure (3): Percentage distribution of studied children' Total quality of life: at Pre- guidelines, Post- guidelines and follow-up phases (n=50)

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**Table (3): Relation between total knowledge scores of studied mothers and their personal characteristics at pre-guidelines, post- guidelines and follow-up phases (n=50).**

Variables	Total knowledge																	
	pre-guidelines					post-guidelines					Follow-Up after three months							
	Adequate (n=14)		Inadequate (n= 36)		X2	P-value	Adequate (n=44)		Inadequate (n=6)		X2	P-value	Adequate (n=41)		Inadequate (n=9)		X2	P-value
	No	%	No	%			No	%	No	%			No	%	No	%		
<b>Mother's age:</b>																		
<20	0	0.0	2	5.6	25.4	0.000	1	2.3	1	16.7	4.9	0.17	1	2.4	1	11.1	2.9	0.40
20-	0	0.0	12	33.3			10	22.7	2	33.3			9	22.0	3	33.3		
30-	3	21.4	19	52.8			19	43.2	3	50.0			18	43.9	4	44.4		
≥40	11	78.6	3	8.3			14	31.8	0	0.0			13	31.7	1	11.1		
<b>Education qualifications:</b>																		
Illiterate	0	0.0	2	5.6	26.1	0.000	1	2.3	1	16.7	3.9	0.41	1	2.4	1	11.1	2.9	0.57
Primary	0	0.0	4	11.1			4	9.1	0	0.0			4	9.8	0	0.0		
Preparatory	0	0.0	8	22.2			7	15.9	1	16.7			6	14.6	2	22.2		
Diploma	2	14.3	18	50.0			17	38.6	3	50.0			16	39.0	4	44.4		
University	12	85.7	4	11.1			15	34.1	1	16.7			14	34.1	2	22.2		
<b>Occupation:</b>																		
House wife	2	14.3	31	86.1	23.1	0.000	31	70.5	2	33.3	3.2	0.09	29	70.7	4	44.4	2.2	0.13
Working	12	85.7	5	13.9			13	29.5	4	66.7			12	29.3	5	55.6		
<b>Residence</b>																		
Rural	3	21.4	29	80.6	15.2	0.000	27	61.4	5	83.3	1.1	0.28	24	58.5	8	88.9	2.9	0.08
Urban	11	78.6	7	19.4			17	38.6	1	16.7			17	41.5	1	11.1		

\*Significant (P<0.05)

\*\* Highly Significant (P<0.001)

**Table (4): Relation between total reported practices scores of studied mothers and their personal characteristics at pre-guidelines, post-guidelines and follow-up phases (n=50).**

Socio-demographic characteristics	Total practice																	
	pre-guidelines					post-guidelines					Follow-Up after three months							
	Satisfactory (n=11)		Unsatisfactory (n= 39)		X2	P-value	Satisfactory (n=43)		Unsatisfactory (n= 7)		X2	P-value	Satisfactory (n=40)		Unsatisfactory (n= 10)		X2	P-value
	No	%	No	%			No	%	No	%			No	%	No	%		
<b>Mother's age:</b>																		
<20	0	0.0	2	5.1	20.6	0.000	1	2.3	1	14.3	2.4	0.48	1	2.5	1	10.0	1.6	0.65
20-	0	0.0	12	30.8			11	25.6	1	14.3			9	22.5	3	30.0		
30-	2	18.2	20	51.3			19	44.2	3	42.9			18	45.0	4	40.0		
≥40	9	81.8	5	12.8			12	27.9	2	28.6			12	30.0	2	20.0		
<b>Education qualifications:</b>																		
Illiterate	0	0.0	2	5.1	22.6	0.000	1	2.3	1	14.3	5.2	0.26	1	2.5	1	10.0	6.2	0.18
Primary	0	0.0	4	10.3			3	7.0	1	14.3			2	5.0	2	20.0		
Preparatory	0	0.0	8	20.5			8	18.6	0	0.0			8	20.0	0	0.0		
Diploma	1	9.1	19	48.7			16	37.2	4	57.1			15	37.5	5	50.0		
University	10	90.9	6	15.4			15	34.9	1	14.3			14	35.0	2	20.0		
<b>Occupation:</b>																		
Working	2	18.2	31	79.5	14.3	0.000	27	62.8	6	85.7	1.4	0.23	26	65.0	7	70.0	0.08	0.76
Housewife	9	81.8	8	20.5			16	37.2	1	14.3			14	35.0	3	30.0		
<b>Residence</b>																		
Rural	1	9.1	31	79.5	18.4	0.000	29	67.4	3	42.9	1.5	0.20	24	60.0	8	80.0	0.53	0.46
Urban	10	90.9	8	20.5			14	32.6	4	57.1			16	40.0	2	20.0		

\*Significant (P<0.05)

\*\* Highly Significant (P<0.001)

**Table (5): Correlation coefficient between total knowledge and total reported practices scores of studied mothers at Pre-guidelines, Post-guidelines and follow-up phases (n=50)**

Variables	Total knowledge					
	Pre-guidelines		Post-guidelines		Follow-Up after three months	
	r	P-value	r	P-value	r	P-value
Total practices	0.85	.000**	0.91	.000**	0.89	.000**

### **Discussion:**

Immune thrombocytopenia (ITP) is an autoimmune disorder characterized by low platelet counts. In children, it is primarily a benign, self-limiting illness that develops after an infectious disease and resolves on its own, without the need for any platelet-enhancing medications, within weeks to months of the onset of the illness. Persistence of thrombocytopenia below 100,000 per microliter for more than 1 year defines the chronic form of the illness (**Beshir et al., 2021**).

Regarding to studied mothers' age, this study showed that more than two fifth of studied mothers were between 30>40 years with Mean age  $\pm$ SD33.68 $\pm$ 7.22. This result is in same line with the research carried out by **Cooper., (2021)** entitled " Immune thrombocytopenia (ITP) World Impact Survey (WIS): Patient and physician perceptions of diagnosis, signs and symptoms, and treatment" and stated that the age of studied mothers was in between 25 to 30 years; while the current study dis agreed with **Schifferli., (2021)** entitled "Misdiagnosed thrombocytopenia in children and adolescents: analysis of the Pediatric and Adult Registry on Chronic ITP", who found that the main age was up 30years old.

Concerning to studied mothers' educational qualifications, according to the existing study, two fifths of the mothers who were studied had secondary education. This outcome disagrees with the study performed by **Giordano et al., (2019)** entitled "A Narrative Approach to Describe QoL in Children with Chronic ITP" who reported that less than half of studied parents were graduated from university.

According to residence of studied mothers, the recent study revealed that less than two thirds of them were living in rural areas. This outcome was in line with study

conducted by **Abdel Raouf et al., (2018)** entitled "Prognostic Clinical and Laboratory Parameters in Children with primary Immune Thrombocytopenic Purpura ", and found that four fifths of the patients were from rural areas; while disagree with the study conducted by **AL-Zuhairy et al., (2013)** entitled " Evaluation of Prognostic Factors in Newly Diagnosed Childhood Primary Immune Thrombocytopenia ITP", and revealed that more than two thirds of the patients diagnosed with ITP were living in urban areas.

Concerning to kinship between studied parents, this study showed that less than two fifths of them had kinship. This result was agreed with the study by **Verstraete., (2020)**, entitled "Item generation for a proxy health related quality of life measure in very young children", and found that there is no relation between the disease and parent's kinship in their study. slightly more than one quarter of cases were in kinship.

Regarding children's age, the existing study Illustrated that, more than half of the studied children were between 4>8 years. This finding agreed with the study conducted by **Sun et al., (2020)**, entitled "Risk Factors and Psychological Analysis of Immune Thrombocytopenia in Children" and found that more than half of children had from two to less than seven years old. Also current study agreed with the study by **Strullu et al., (2013)**, entitled " Evaluation of health related quality of life in children with immune thrombocytopenia with the PedsQL Generic Core Scales", and found that more than half of the studied children were between 4>8 years ; while this study in disagreement with **Gao et al., (2020)**, who carried out study titled "Measuring parent proxy-reported quality of life of 11 diseases in children in Zhejiang, China", and found that less than half of studied children with ITP were in age between two to four years .

Regarding to children's gender, this study clarified that more than three fifths of studied children were males. This finding agreed with the study done by **Abdel Raouf et al., (2018)** entitled " Prognostic Clinical and Laboratory Parameters in Children with primary Immune Thrombocytopenic Purpura " and showed that more than three fifths of the studied children were males .Also agreed with the study done by **Wiseman et al., (2002)** entitled "Ibritumomab tiuxetan radio immunotherapy for patients with relapsed or refractory non-Hodgkin lymphoma and mild thrombocytopenia: a phase II multicenter trial", and found that three fifths of studied children were males . As opposed to that, the existing study disagreed with **Yasser et al., (2020)** who carry out study entitled " Analysis of Lines of Treatment & Outcome of Chronic Immune thrombocytopenic purpura in Mansoura University Children's Hospital: A Retrospective Study ", and found that females were slightly predominant than males, they represented more than half of sample. On contrary to the result the study done by **Makis et al., (2017)** entitled" Prognostic Factors for Immune Thrombocytopenia Outcome in Greek Children" and the study done by **Abdelmabood & Sarhan, (2018)** entitled "The use of anti-CD20 in management of Egyptian children with chronic immune thrombocytopenic purpura" stated equal sex distribution among newly diagnosed cases.

Concerning on studied mothers' total knowledge regarding thrombocytopenia, the existing study presented that, more than one quarter of studied mothers had adequate level of knowledge in pre- guidelines phase, more than four fifths of them had adequate level of knowledge in post-guidelines and follow-up phases respectively. This finding agreed with the study done by **Gruhn et al., (2021)** entitled "Successful Use of Eltrombopag in a Young Child with Chronic Immune

Thrombocytopenia", and found that more than one third of mothers who have been studied had adequate level of knowledge in pre-intervention phase which increased to less than two thirds of them had adequate level of knowledge in post-intervention phase.

Concerning on mothers' total reported practices regard immune thrombocytopenia, the current study showed that there was highly statistically significant improvement in mothers' total reported practices regarding ITP in post guidelines and follow up phases compared with pre guidelines phase. This finding was agreement with the study done by **Huang et al., (2020)**, entitled "Personality, behavior characteristics and life quality impact of children with dyslexia", and found that majority of mothers, had unsatisfactory practice about immune thrombocytopenia. Also, this result was accordance with the study by **Kühne, (2017)**, entitled "Diagnosis and management of immune thrombocytopenia in childhood", and found that there was highly statistically significant improvement in mothers' practice regarding immune thrombocytopenia in post intervention phase.

Regarding to studied children' total quality of life, the present study showed that there was significant difference in mean scores of total quality of life in children with immune thrombocytopenia in all items in post guidelines and follow up compared with pre guidelines. This finding is in line with the research conducted by **Grainger et al., (2019)** entitled "Health related quality of life in children with chronic immune thrombocytopenia treated with eltrombopag in the PETIT study", and found that there was significant difference in mean scores of total quality of life in children with immune thrombocytopenia in post intervention compared with pre intervention.

Concerning on relation between total knowledge scores of studied mothers and their socio-demographic characteristics, the current study clarified that, there was a highly statistically significant relation between total knowledge score of the studied mothers and their socio demographic characteristics at pre-guideline phase ( $P < 0.001$ ) compared to no statistically significant relation at post-guideline phase ( $P > 0.05$ ). Moreover, there was no statistically significant relation between studied mothers' total knowledge and socio demographic characteristics at follow-up phases ( $P > 0.05$ ). these findings in agreed with the research by **Uemura et al., (2020)** entitled "An infant with refractory cytomegalovirus-induced thrombocytopenia", and found that there was a highly statistically significant relation between total knowledge score of the studied mothers and their socio demographic characteristics at pre-intervention phase ( $P < 0.001$ ) compared to no statistically significant relation at post-intervention phase ( $P > 0.05$ ).

As for relation between total reported practices scores of studied mothers and their socio-demographic characteristics, the current study clarified that, there was a highly statistically significant relation between total practice score of the studied mothers and their socio demographic characteristics at pre-guideline phase ( $P < 0.001$ ) compared to no statistically significant relation at post-guideline phase ( $P > 0.05$ ). Moreover, there was no a statistically significant relation between studied mothers' total practice and socio demographic characteristics at follow-up phases ( $P > 0.05$ ) . The current result agrees with **Hinson & Saxonhouse, (2019)** who done research entitled "Neonatal thrombosis after antenatal treatment of neonatal all immune thrombocytopenia with intravenous immunoglobulin", and found that there was a highly statistically significant

relation between total practice score of the studied mothers and their socio demographic characteristics at pre-intervention phase ( $P < 0.001$ ) compared to no statistically significant relation at post-intervention phase ( $P > 0.05$ )

### **Conclusion:**

The majority of studied mothers had adequate level of knowledge and satisfactory level of reported practice immediately posttest and three months after implementation of designed guidelines compared with pre guidelines implementation. Additionally, more than two thirds of studied children had positive quality of life in post guidelines and follow up phases compared with pre guidelines phase.

### **Recommendations**

- Providing guidelines for mothers of children with immune thrombocytopenia in hospitals, outpatient clinics and care settings.
- More research is required to teach mothers how to properly care for their children who have immune thrombocytopenia, increase their awareness of the condition's nature, various management options, complications, and prognosis, and teach them what actions to take in various daily situations.
- Follow up program for children with Immune thrombocytopenia should be implement and organized in the hospitals, for the proper management application, prognosis of thrombocytopenia, relieving of the signs and symptoms and prevent its complications.
- Further studies are needed for enhancing good quality of life for children with immune thrombocytopenia.

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## تحسين جودة حياة الأمهات وأطفالهن المصابين بنقص الصفائح الدموية المناعي

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نقص الصفائح الدموية المناعي هو مرض مناعي ذاتي يتميز بانخفاض عدد الصفائح الدموية عن المعدل الطبيعي لها. وترتبط هذه الحالة بأعراض مثل الكدمات ، والنزيف الانفي ، ونزيف الغشاء المخاطي من الجهاز الهضمي والمسالك البولية مما يؤثر بدوره علي جودة حياة الأطفال المصابين. وقد هدفت هذه الدراسة إلى تحسين جودة حياة الأمهات وأطفالهن المصابين بنقص الصفائح الدموية المناعي. وقد تم إعداد تصميم شبه تجريبي للدراسة. وقد أجريت هذه الدراسة بمستشفى الأطفال التخصصي ببنها التابعة لأمانة المراكز الطبية المتخصصة (في العيادات الخارجية و قسم أمراض الدم).وقد أجريت هذه الدراسة علي 50 أم و أطفالن الذين يعانون من نقص الصفائح الدموية المناعي والذين تتراوح أعمارهم من 2 الي أقل من 18 عامًا. وقد أظهرت النتائج أن أقل من ربع الأمهات الخاضعات للدراسة كان لديهن مستوى مرض من الممارسة في مرحلة ما قبل الإرشادات ، وكانت غالبية الأمهات اللاتي شملتهن الدراسة لديهن مستوى مرضي من الممارسة بعد إعطاء الارشادات ، وأكثر من ثلاثة أرباع الامهات لديهن مستوى مرض من الممارسة لتحسين جودة حياة أطفالهن الذين يعانون من نقص الصفائح الدمويه في مرحلة المتابعة. أيضا كشفت النتائج أن أقل من نصف الأطفال الخاضعين للدراسة لديهم جودة حياة إيجابية في مرحلة ما قبل الإرشادات ، بينما الغالبية منهم لديهم جودة حياة إيجابية في مرحلة ما بعد الإرشادات وأكثر من ثلاثة أرباع الأطفال لديهم جودة حياة إيجابية في مرحلة المتابعة. وقد أوضحت الدراسة في توصيتها أن هناك حاجة إلى مزيد من الأبحاث لتدريب الأمهات حول الرعاية المناسبة للأطفال الذين يعانون من نقص الصفائح الدموية المناعي وزيادة وعيهم حول طبيعة المرض والممارسات الصحيحة في المواقف المختلفة اليومية.