

## **Effect of Self -Determination Theory Based Intervention on Self- Care Among School Age Children with Thalassemia**

**Samar F. Badawy<sup>1</sup>, Omayma M. Okby<sup>2</sup>, Taghreed K. Omar<sup>3</sup>,  
Fatma A. Ahmed<sup>4</sup>**

<sup>1</sup>Assistant lecturer of Pediatric Nursing, <sup>2</sup>Professor of Pediatric Nursing,  
<sup>3</sup>Emeritus Professor of Pediatric Nursing, <sup>4</sup>Assistant professor of Pediatric Nursing,

<sup>1,2,3,4</sup> Faculty of Nursing, Menoufia University, Egypt

**Abstract: Background:** Self- determination theory (SDT) play an integral role in the management of many children with thalassemia. **Purpose:** The purpose of the study was to assess the effect of the self- determination theory based intervention on self – care among school age children with thalassemia. **Research Design:** A quasi experimental design was used. **Setting:** It was conducted the pediatric thalassemia unit in Menoufia University Hospital. **Sample:** Purposive sample of 70 children with thalassemia at the previously mentioned setting. **Instruments:** Three data collection instruments were used: structured interviewing questionnaire, Basic Psychological Needs Satisfaction and Frustration Scale and Self Care Assessment Worksheet. **Results:** the result of this study showed that there were very highly statistical significant differences between children's knowledge on posttest compared to pretest ( $3.6\pm 1.1$  Vs  $1.7\pm 0.6$  respectively). Also, children who received self- determination theory based intervention had improved their autonomy, relatedness, and competency and self-care practices. **Conclusion:** It was concluded that implementation of self- determination theory improved knowledge and self- care for children with thalassemia on post and follow-up tests than pretest. **Recommendation:** self- determination theory based intervention about thalassemia should be developed and provided for children in pediatric thalassemia units.

**Key words:** *Self- Determination Theory, Self-care, Thalassemia.*

### **Introduction**

Thalassemia is the most common hemoglobin disorder in the world. It is an inherited disease, where if the parents are carriers or affected, their children will have high probability of being affected too. It is a chronic illness that affects greatly many children's health that requires frequent attention from physicians or other health professionals, as well as regular use of medication (Elsoudy et al., 2022) . Different types of thalassemia lead to diverse disorders in children. The most severe form of thalassemia, beta- thalassemia major, will most likely cause multiple health complications. Thalassemia is a severe

public health problem in the Mediterranean area, in addition to has no cure (Raza et al., 2015).

Thalassemia is one of health problem, worldwide it occurs in 4.4/10,000 live births. About 66.0% of children were under 15 years old. It affects approximately 200 million children worldwide. Globally, there are about 240 million carriers of  $\beta$ -thalassemia. In the United States, it was reported that 1: 272, 000 live births had thalassemia (Sahmoud et al., 2020).

In Egypt,  $\beta$ -thalassemia is considered the most common monogenic disorder with a carrier rate of almost 5.3 to 9.0 %, representing the most common

genetically determined chronic hemolytic anemia (85.1%) and 1–5 million neonates are anticipated to be affected with this illness, (Ragb et al., 2021). A high rate of carriers has been reported ranging from 4–5% reaching up to 9–10% (Shanshory et al., 2021). Thalassemia has an effect on the formation of the globin chain. Signs symptoms may vary depending on the number and type of chains involved (Safizadeh et al., 2012). Thalassemia usually accompanied by physiological changes in the body structures of children with severe diseases related to hemochromatosis such as growth retardation and delayed or absent sexual maturation in many adolescents. Moreover, most children treated with blood transfusion and early chelation therapy survives well into adulthood. The most common causes of death are heart diseases, post-splenectomy sepsis, and multi organ failure secondary to hemochromatosis (Wilson et al., 2011). Thalassemic children have more depressive symptoms and lower quality of life (QOL). Also, aggression and shyness are higher in those children than healthy ones. Moreover, anxiety and depression were in 47% of them, this brought about problems in their self-care and QOL (Borhani et al., 2011). Thalassemia not only affects the child's physical performance but also school achievement, emotional functioning in addition to social aspects (Kahouei et al., 2016). Management strategies of beta-thalassemia major emphasis on just how to treat its manifestations and chronic complications using the best current treatment approaches, transfusion therapy, oral iron chelation therapy, splenectomy, , in addition to hematopoietic stem cell transplantation (Eliezer et al., 2016). Transfusion requirements increase with time and children develop iron overload for

which children require chelation (Naggarwal et al., 2011). Blood transfusion aims to promote normal growth and chelating agents are capable of removing excessive iron from the body (Navaneetha et al., 2013). Thalassemia has no cure, so the goal of treatment is to normalize the hemoglobin and hematocrit of the child, thus alleviating the symptoms of severe anemia. This is accomplished via a regular schedule of transfusions, with many children requiring transfusions every 2 to 3 weeks (Potts et al., 2012).

Self-management of care and adherence to treatment is a vital need for children to maintain and promote their health, prevent the complications and promote their life (Hock, Kinsman & Ortaglia, 2015). It includes the impact of illness, medical therapy or services and promotes the ability to participate as well as satisfaction in all dimensions of life (Patric et al., 2010). Self-determination theory (SDT) is an empirically based theory of motivation and psychological development that is especially focused on the basic psychological needs (autonomy, competence and relatedness) that promote high quality motivation and wellness, and how they are supported in social contexts. Thalassemia children need to regulate their own actions regarding his condition, development of securing and satisfying connections with others, adhere to treatment regimen and maintain a healthy lifestyle to have better self-care (Ryan & Deci (2017).

### **Significance of the study**

Thalassemia is an inherited blood disease. It is a serious health problem throughout the Mediterranean region, the Middle East and the Southeast Asia (Behdani et al., 2015). There is approximately 300 million carriers of this hemoglobin disorder worldwide

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

(Kavitha & Padmaja, 2017). In Egypt, thalassemia is the most common genetically inherited hemoglobin disorder with a carrier rate ranging from 0.5% to more than 9% and 1000 children out of 1.5 million live births are born annually with thalassemia major (De Sanctis et al., 2017). School age children with thalassemia want to have more control over their body; they ask many questions about procedures, investigations and treatment (Wilcox & Verhovsek, 2012). Limited studies were conducted in this aspect. Therefore, this study will assess the effect of self-determination theory based intervention on self-care and quality of life among school age children with thalassemia.

**Purpose**

The purpose of this study is to assess the effect of the self-determination theory based intervention on self-care among school age children with thalassemia.

**Research Hypothesis:**

- Children with thalassemia who receive the self-determination theory based intervention will have higher level of knowledge on posttest than pretest.
- Children with thalassemia who receive the self-determination theory based intervention will have higher level of autonomy, relatedness and competency on posttest than pretest.
- Children with thalassemia who receive the self-determination theory based intervention will have higher level of self-care practices on posttest than pretest.

**Methods**

**Research Design:**

A quasi-experimental design (pre and posttest) was utilized for this study.

**Sampling:**

Purposive sample of 70 children with thalassemia at previously mentioned setting and who agree to participate in the study and meet the criteria of sample selection will be included).

**Instruments:-**

Three instruments were utilized for data collection:

**Instrument one: A structured interviewing questionnaire to assess general characteristics of the studied sample:**

It was developed by the researcher guided by Zaghmir et al., (2019). It consisted of two parts:

- **Part one:** Socio-demographic characteristics of studied children. It included questions about age, gender, diagnosis, Suffer from other diseases, Consanguinity with parents, family history of thalassemia, family history of blood diseases, time of starting treatment, hemoglobin level, number of blood transfusion / year and spleen removal.
- **Part two:** Children knowledge about thalassemia. It included knowledge assessment items such as: definition of thalassemia, causes, types, symptoms, Management and prevention of thalassemia.

**Total Scoring system (0-5):**

<i>Scoring items</i>	<i>Score</i>
Good knowledge (4-5)	> 75%
Fair knowledge (3)	≤75%
Poor knowledge (0-2)	≤ 50%

**Reliability of Instrument 1:**

Reliability was estimated by using test retest method with two weeks apart between them. Then Cronbach alpha was calculated between the two scores using SPSS computer package. It was

**Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia**

0.85 which indicates that the instrument is reliable for the study.

**Instrument 2: Basic Psychological Needs Satisfaction and Frustration Scale (BPNSFS):**

It was adopted from Ryan & Deci (2000) & Vansteenkiste, et al., (2015) to assess child's autonomy, relatedness and competency either satisfaction or frustration. Each item contains 4 questions and rated on a 4-point Likert scale.

**Total scoring system for each item (4-16):**

<i>Scoring items</i>	<i>Score</i>
High autonomy satisfaction (13 – 16)	≥ 60%
Moderate autonomy satisfaction (10-12)	30% to < 60%
Low autonomy satisfaction (4- <10)	< 30%

**Reliability of Instrument 2:**

Reliability was estimated by using test retest method with two weeks apart between them. Then Cronbach alpha was calculated between the two scores. It was 0.81 which indicates that the instrument is reliable for the study.

**Instrument 3: Self Care Assessment**

**Worksheet:**

It was developed by the researcher guided by Saakvitne & Pearlman (1996). It is a structured interviewing questionnaire. It consisted of four dimensions such as physical self-care (42Q), Psychological self-care (9Q), Social self-care (4Q) and school self-care (6Q). Each item was rated on a 3-point Likert scale.

**Total scoring system of Physical self-care (42-126):**

<i>Scoring items</i>	<i>Score</i>
High physical self-care	99 – 126
Moderate physical self-care	79 – 98
Low physical self-care	42- 78

**Total scoring system of Psychological self-care (9-27):**

<i>Scoring items</i>	<i>Score</i>
High Psychological self-care	21 – 27
Moderate Psychological self-care	17 – 20
Low Psychological self-care	9- 16

**Total scoring system of social self-care (4-12):**

<i>Scoring items</i>	<i>Score</i>
High social self-care	10 – 12
Moderate social self-care	8 – 9
Low social self-care	4- 7

**Total scoring system of School self-care (6-18):**

<i>Scoring items</i>	<i>Score</i>
High School self-care	15 – 18
Moderate School self-care	12 – 14
Low School self-care	6- 11

**Reliability of Instrument 3:**

Reliability was estimated by using test retest method with two weeks apart between them. Then Cronbach alpha was calculated between the two scores using SPSS statistical package. It was 0.86 which indicates that the instrument is reliable for the study.

**Validity**

For validity assurance, instruments were submitted to a jury of five experts in the Medical and Nursing field (3 professors in nursing and 2 professors in medicine) to modify any required items of the instruments .The modifications were done to ascertain their relevance and completeness.

**Ethical considerations**

- An initial approval was obtained from the Ethical Research Committee in the Faculty of Nursing, Menoufia University
- A written consent was obtained from the parents of children who will participate in the study.
- An initial interview done to inform children and their parents about the purpose, benefits of the study and explain that participation in the study

was voluntary and the participants can withdraw from the study at any time without penalty.

### **Pilot study**

It was carried out on 7 children (10% of the sample) after the instruments were developed and before starting the data collection to test the practicability, applicability and to estimate the needed time to fill the instruments.

### **Procedure**

#### **Assessment phase:**

1. Prior to data collection, a written permission to carry out the study was obtained from the director of the unit after submitting an official letter from the Dean of the Faculty of Nursing at Menoufia University explaining the purpose of the study and methods of data collection.
2. Data collection for this study was conducted over a period of five months extending from 1st of September, 2021 to the end of February, 2022.
3. The researcher introduced herself to the studied children and their parents. The purpose of the study and methods of data collection was explained to them.
4. The researcher interviewed each child and fulfilled the structured interviewing questionnaire regarding their knowledge about thalassemia using instrument 1. It took 15 minutes to fulfill (pretest).
5. Instrument 2 was used by the researcher to assess children basic psychological needs (autonomy, relatedness and competency) (pretest).
6. Children self-care regarding thalassemia was assessed by the researcher using instrument 3 (pretest).

#### **Implementation phase:**

- Based on assessment of children knowledge weakness and practice defects the intervention based on Self-determination theory was designed accordingly.
- Health teaching sessions were started by the researcher to all children with thalassemia at the Pediatric Thalassemia Unit. Each session included 7-8 children. Each child received 8 sessions (2sessions for theoretical part and 6 sessions for practical part) (2 sessions /week). Each session lasted for 20 to 30 minutes. Oral presentations, group discussions, smart phone, demonstration and re-demonstration and feedbacks were used for health education also, explanatory booklets were distributed between children.
  - The first session contained theoretical knowledge related to thalassemia e.g. definition, causes, types, signs, symptoms and complications of thalassemia. It lasts about 30 minutes.
  - The second session contained theoretical knowledge related to management of thalassemia, benefits and complications of blood transfusion. It lasts about 30 minutes.
  - The third session about practical part of applying self-determination theory to improve children's autonomy through encouraging and motivating the child to participate in their own care and giving them freedom to participate in his their decisions .It lasts about 20 minutes.
  - The fourth session about practical part of applying self-determination theory to improve children's relatedness through encouraging the family to support the child to participate in his self-care and allow family to involve in their child care. It lasts about 20 minutes.

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

- The fifth session about practical part of applying self-determination theory to improve children's competency through training the child on how to take medicine and follow up any side effects and Participate in activities related to his care such as blood transfusions. It lasts about 20 minutes.
- The sixth session about practical part to improve children self-care practices (physical self-care) through using demonstration and re-demonstration about diet, exercise, medication, hygiene and discussion about rest, sleep and infection. It lasts about 25 minutes.
- The seventh session about practical part to improve children self-care practices (psychological and social self-care) through panel discussion about having warm supportive relationships with friends and family members, share feelings with favorite person, spend time with the loved people and avoid isolation. It lasts about 20 minutes.
- The eighth session about practical part to improve children self-care practices (school self-care). Through following the guidelines such as frequent check up with physician to manage any problem so that the illness does not affect school going, do homework firsthand to avoid any difficulty and ask help from friends in lessons that children did not pass. It lasts about 15 minutes.
- The researcher provided summary about knowledge provided in the first session. Afterwards, nursing care interventions based on Self-determination theory about achieving children autonomy, competency and relatedness in self-care approaches were discussed.
- Direct reinforcement was used in the form of chocolates and pens were distributed between children.
- Also each session ended by a summary of its contents and feedback from the children was obtained to ensure that they got the maximum benefit.
- Explanatory booklet that used was translated into Arabic by the researcher and was distributed to all children.

**Evaluation phase:**

- 1) Reassessment of children knowledge regarding thalassemia was done immediately following the health education sessions by the researcher to each child individually within the group using instrument 1 (posttest).
- 2) Reassessment of children's autonomy, relatedness, and competency was done to each child individually within the group after 30 days of intervention using instrument 2 (posttest).
- 3) Reassessment of children's self-care was done to each child individually within the group after 30 days following the health education sessions by the researcher using instrument 3 (posttest).
- 4) Reassessment of children' knowledge, autonomy, relatedness, competency, self-care were done three months later to each child individually within the group by the researcher using instrument 1,2& 3 (follow up test).

**Statistical analysis:**

Data was entered and analyzed by using SPSS (Statistical Package for Social Science) statistical package version 22. Graphics were done using Excel program.

Quantitative data were presented by mean (X) and standard deviation (SD). It was analyzed using student t- test for comparison between two means, and ANOVA (F) test for comparison between more than two means.

Qualitative data were presented in the form of frequency distribution tables, number and percentage. It was analyzed by chi-square ( $\chi^2$ ) test. However, if an expected value of any cell in the table was less than 5, Fisher Exact test was used (if the table was 4 cells), or Likelihood Ratio (LR) test (if the table was more than 4 cells). Level of significance was set as P value  $<0.05$  for all significant tests.

## **Results**

**Table 1:-** showed characteristics of studied children. It was obvious from this table that 35.7% of the studied children with thalassemia aged between 6 to 8 years with mean age  $9.1 \pm 1.8$  years and more than half were females (55.7%).

**Table 2:-** reveals Medical data of studied children. As illustrated in the table, nearly two third of children diagnosed with thalassemia since more than 5 years (64.3%), with a mean duration of  $6.2 \pm 1.5$  years, and nearly half of them had Consanguinity with parents (45.7%). Also, approximately one third had family history of thalassemia (28.6%). Meanwhile; more than half of children had low hemoglobin level before blood transfusion (58.6%) and the majority of them had spleen removal.

**Table 3:-** displays Children knowledge about thalassemia on pre, post, and follow up tests. The findings revealed that children had higher level of knowledge about thalassemia on post and follow-up tests than on pretest. Therefore, there were highly statistical significant differences between children 'knowledge on posttest than pretest regarding definition, causes, types, symptoms, management and prevention of thalassemia ( $P < 0.0001$ ). However, there were no statistical significant differences regarding children 'knowledge between posttest and follow-up test.

**Table 4:-** displays Mean total score of children knowledge on pre, post and follow up tests. The findings revealed that there were highly statistical significant differences between pretest and posttest ( $P < 0.0001$ ). Also, there were highly statistical significant differences between pretest, posttest and follow-up test ( $P < 0.0001$ ). However, there were no statistical significant differences between posttest and follow-up test ( $P > 0.05$ ).

**Table 5:-** displays Assessment of thalassemia children's Autonomy level of satisfaction and frustration on pre, post and follow-up tests based on self-determination theory. The findings revealed that there were highly statistical significant differences regarding levels of autonomy satisfaction on pre, post and follow up tests ( $P < 0.001$ ). Also, there were highly statistical significant differences regarding levels of autonomy frustration on pre, post and follow up tests ( $P < 0.001$ ).

**Table 6:-** displays Assessment of thalassemia children's Relatedness level of satisfaction and frustration on pre, post and follow up tests based on self-determination theory. The findings revealed that there were statistical significant differences regarding levels of relatedness satisfaction on pre, post and follow up tests ( $P < 0.05$ ).

**Table 7:-** displays Assessment of thalassemia children's Competency on pre, post and follow up tests based on self-determination theory. The findings revealed that there were statistical significant differences regarding levels of Competency satisfaction on pre, post and follow up tests ( $P < 0.05$ ). Also, there were statistical significant differences regarding levels of Competency frustration on pre, post and follow up tests ( $P < 0.05$ ).

**Table 8:-** displays descriptive statistics of the eight dimensions of the physical self-care among studied thalassemia

children on pre, post and follow up tests. As clarified in the table, mean score of clothes was 11.8 and 11.6 on post and follow-up tests compared to 10.4 on pretest. So, there was statistical significant differences between mean score on post and follow-up test than pretest ( $P < 0.05$ ). Also, mean score of dental care was 4.8 and 4.6 on post and follow-up tests compared to 4.2 on pretest. So, there was statistical significant differences between mean score on post and follow-up test than pretest ( $P < 0.05$ ). Regarding Total score of Medication it was 10.8 and 10.7 on posttest and follow up test compared to 10.2 on pretest. So, there was statistical significant differences between mean score on post and follow-up test than pretest ( $P < 0.05$ ). Regarding Total score of avoid infection it was 14.9 and 14.6 on posttest and follow up test compared to 11.4 on pretest. So, there was statistical significant differences between mean score on post and follow-up test than pretest ( $P < 0.05$ ).

**Table 9** :- displays Levels of self-care dimensions among studied children on pre, post and follow up tests. Regarding Psychological Self-Care the findings revealed that there were highly statistical significant differences on pre, post and follow-up tests ( $P < 0.001$ ). Also, there were statistical significant differences on pre, post and follow-up tests regarding school Self-

Care ( $P < 0.05$ ). Meanwhile there were highly statistical significant differences regarding total mean of psychological, social and school self-care levels on pre, post and follow-up tests ( $P < 0.001$ ).

**Table 10 and Fig.1** revealed levels of physical self-care among studied children on pre, post and follow up tests. As clarified in the table, Posttest revealed a highly significant improvement ( $p < 0.0001$ ) in the physical self-care groups. Mean score of high physical self-care was 34.3% and 32.9% on post and follow-up tests compared to 15.7% on pretest. So, there was very highly statistical significant differences between mean score of physical self-care on post and follow-up test than pretest ( $P < 0.0001$ ). In addition, mean score of low physical self-care was 2.9% and 4.3 % on post and follow-up tests compared to 22.9% on pretest. So, there was very highly statistical significant differences between mean score on post and follow-up test than pretest ( $P < 0.0001$ ). Moreover, the mean score of total physical self-care increased from  $88.9 \pm 14.1$  pretest to  $95.6 \pm 11.3$  posttest, and  $94.9 \pm 11.3$  in follow-up test, and the difference was highly significant ( $P < 0.001$ ).

*Effect of Self -Determination Theory Based Intervention on Self- Care Among School Age Children with  
Thalassemia*

**Table (1): Characteristics of studied children (N = 70).**

Children characteristics	N0 70	%
<b>Age (Years)</b>	25	35.7
6 – 8 years	23	32.9
9 – 10 years	22	31.4
11 – 12 years		
<b>Mean ± SD= 9.1 ± 1.8 years (Range=6-12 years)</b>		
<b>Gender</b>		
Male	31	44.3
Femal	39	55.7
<b>Total</b>	70	100

**Table (2): Medical data of studied children (N = 70).**

Medical data	N0 70	%
<b>Duration since diagnosed with thalassemia:</b>	7	10
1- 3 years	18	25.7
4 -6 years	45	64.3
> 6 years		
<b>Mean ± SD</b>		
	6.5 ± 2.1 years	
<b>Suffer from other diseases:</b>	No	%
No	100	10
Yes	0	0
<b>Consanguinity with parents:</b>	32	45.7
Yes	38	54.3
No		
<b>Family history of thalassemia:</b>	20	28.6
Yes	50	71.4
No		
<b>Time of starting treatment:</b>	28	40
≤ 5 years	42	60
> 5 years		
<b>Child hemoglobin level before blood transfusion:</b>	41	58.6
< 7 mg/dl	20	28.5
7 – >8 mg/dl	9	12.9
8- 9 mg/dl		
<b>Number of blood transfusion / year:</b>	6	8.6
Every 15 days	41	58.5
Every 30 days	23	32.9
Every 45 days		
<b>Spleen Removal</b>	45	64.3
Yes	25	35.7
No		
<b>Total</b>	<b>70</b>	<b>100</b>

*Effect of Self -Determination Theory Based Intervention on Self- Care Among School Age Children with Thalassemia*

**Table (3): Children knowledge about thalassemia on pre, post, and follow up tests (N = 70).**

Children's knowledge about thalassemia	Pretest		Posttest (Immediate- posttest)		P1	Follow-up Test		P2
	No 70	%	No 70	%		No 70	%	
<b>Definition of thalassemia</b>								
Incorrect answer	25	35.7	6	8.6	$\chi^2 = 14.9$	8	8.6	$\chi^2 = 1.1$
Correct answer	45	64.3	64	91.4	P < 0.0001 HS	62	91.40	P = 0.23 NS
<b>Causes of thalassemia:</b>								
Incorrect answer	47	67.1	28	40	$\chi^2 = 10.4$	31	44.3	$\chi^2 = 0.12$
Correct answer	23	32.9	42	60	P < 0.0001 HS	39	55.7	P = 0.73 NS
<b>Types of thalassemia:</b>								
Incorrect answer	56	80	30	42.9	$\chi^2 = 20.4$	36	51.4	$\chi^2 = 0.71$
Correct answer	14	20	40	57.1	P < 0.0001 HS	34	48.6	P = 0.39 NS
<b>Symptoms of thalassemia:</b>								
Incorrect answer	33	47.1	30	42.9	$\chi^2 = 3.6$	32	45.7	$\chi^2 = 2.3$
Correct answer	37	52.9	40	57.1	P = 0.7 NS	38	54.3	P = 0.9 NS
<b>Management of thalassemia:</b>								
Incorrect answer	47	67.1	20	28.6	$\chi^2 = 20.9$	25	35.7	$\chi^2 = 2.5$
Correct answer	23	32.9	50	71.4	P < 0.0001 HS	45	64.3	P = 0.11 NS
<b>Prevention of thalassemia:</b>								
Incorrect answer	52	74.3	17	24.3	$\chi^2 = 35.1$	24	34.3	$\chi^2 = 1.2$
Correct answer	18	25.7	53	75.7	P < 0.0001 HS	46	65.7	P = 0.26 NS
<b>Services offered to you</b>								
No	15	21.4	10	14.2	$\chi^2 = 0.6$	12	17.1	$\chi^2 = 0.10$
Yes	55	78.6	60	85.7	P = 0.43 NS	58	82.9	P = 0.70 NS
<b>Kind of services (N=55):</b>								
Fund	16	22.9	14	20	$\chi^2 = 0.4$	14	20	$\chi^2 = 0.5$
Health	14	20	17	24.3	P = 0.42 NS	17	24.3	P = 0.43 NS
Social	7	10	4	5.7		6	8.5	
All	33	47.1	35	50		33	47.1	
<b>Total</b>	<b>70</b>	<b>100</b>	<b>70</b>	<b>100</b>		<b>70</b>	<b>100</b>	

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

**Table (4): Mean total score of children knowledge on pre, post and follow up tests.**

Mean total score	Pretest	Posttest (Immediate-posttest)	P1	Follow-up test	P2	P3
Mean total score of children knowledge	1.7±0.6	3.6±1.1	t=12.6 p< 0.0001 HS	3.3±1.1	t=1.2 p2=0.14 NS	F=43.5 P3<0.0001 HS

**Table (5): Assessment of thalassemic children's Autonomy level of satisfaction and frustration on pre, post and follow-up tests based on self-determination theory.**

Basic Psychological Needs: (Autonomy)	Intervention groups						Test of significance
	Pretest No (70) %		Posttest (after 30 days) No (70) %		Follow -up test No (70) %		
<b>Groups of Total Autonomy Satisfaction</b>							
Low Autonomy Satisfaction (<10)	52	74.3	35	50	46	65.7	LR=9.6 P<0.002 HS.
Moderate Autonomy Satisfaction (10 - 12)	7	10	22	31.4	11	15.7	
High Autonomy Satisfaction (13 - 16)	11	15.7	13	18.6	13	18.6	
<b>Groups of Total Autonomy Frustration</b>							
Low Autonomy Frustration (<10)	40	57.1	45	64.3	42	60	LR=14.3 P<0.007 HS
Moderate Autonomy Frustration (10 - 12)	20	28.6	10	14.3	13	18.6	
High Autonomy Frustration (13 - 16)	15	21.4	15	21.4	15	21.4	
<b>Total</b>	<b>70</b>	<b>100</b>	<b>70</b>	<b>100</b>	<b>70</b>	<b>100</b>	

**Effect of Self -Determination Theory Based Intervention on Self- Care Among School Age Children with Thalassaemia**

**Table (6): Assessment of thalassaemic children’s Relatedness level of satisfaction and frustration on pre, post and follow-up tests based on self-determination theory.**

Basic Psychological Needs: (Relatedness)	Intervention groups						Test of significance
	Pretest		Posttest (after 3 days)		Follow up- test		
	No (70) %		No (70) %		No (70) %		
<b>Groups of Total Relatedness Satisfaction</b>							
Low Relatedness Satisfaction (<10)	49	70	31	44.3	42	60	$\chi^2 = 3.3$ P=0.04 S
Moderate Relatedness Satisfaction (10 - 12)	17	24.3	33	47.1	22	31.4	
High Relatedness Satisfaction (13 - 16)	4	5.7	6	8.6	6	8.6	
<b>Groups of Total Relatedness Frustration</b>							
Low Relatedness Frustration (<10)	40	57.1	47	67.1	40	57.1	$\chi^2 = 0.7$ p=0.40 NS
Moderate Relatedness Frustration (10 - 12)	15	21.4	10	14.3	15	21.4	
High Relatedness Frustration (13 - 16)	15	21.4	13	18.6	15	21.4	
<b>Total</b>	<b>70</b>	<b>100</b>	<b>70</b>	<b>100</b>	<b>70</b>	<b>100</b>	

**Table (7): Assessment of thalassaemic children’s Competency level of satisfaction and frustration on pre, post and follow-up tests based on self-determination theory.**

Basic Psychological Needs (Competency)	Intervention groups						Test of significance
	Pretest		Posttest (after 30 days)		Follow up- test		
	No (70) %		No (70) %		No (70) %		
<b>Groups of Total Competence Satisfaction</b>							
Low Competence Satisfaction (<10)	50	71.4	40	57.1	42	60	$\chi^2 = 2.3$ P=0.01 S.
Moderate Competence Satisfaction (10 - 12)	10	14.3	15	21.4	14	20	
High Competence Satisfaction (13 - 16)	10	14.3	15	21.4	14	20	
<b>Groups of total Competence Frustration</b>							
Low Competence Frustration (<10)	53	90	57	71.4	55	78.6	LR=11.5 P<0.02 S.
Moderate Competence Frustration (10 -12)	10	5.7	7	25.7	8	11.4	
High Competence Frustration (13 - 16)	7	10	6	8.6	7	10	
<b>Total</b>	<b>70</b>	<b>100</b>	<b>70</b>	<b>100</b>	<b>70</b>	<b>100</b>	

*Effect of Self -Determination Theory Based Intervention on Self- Care Among School Age Children with  
Thalassemia*

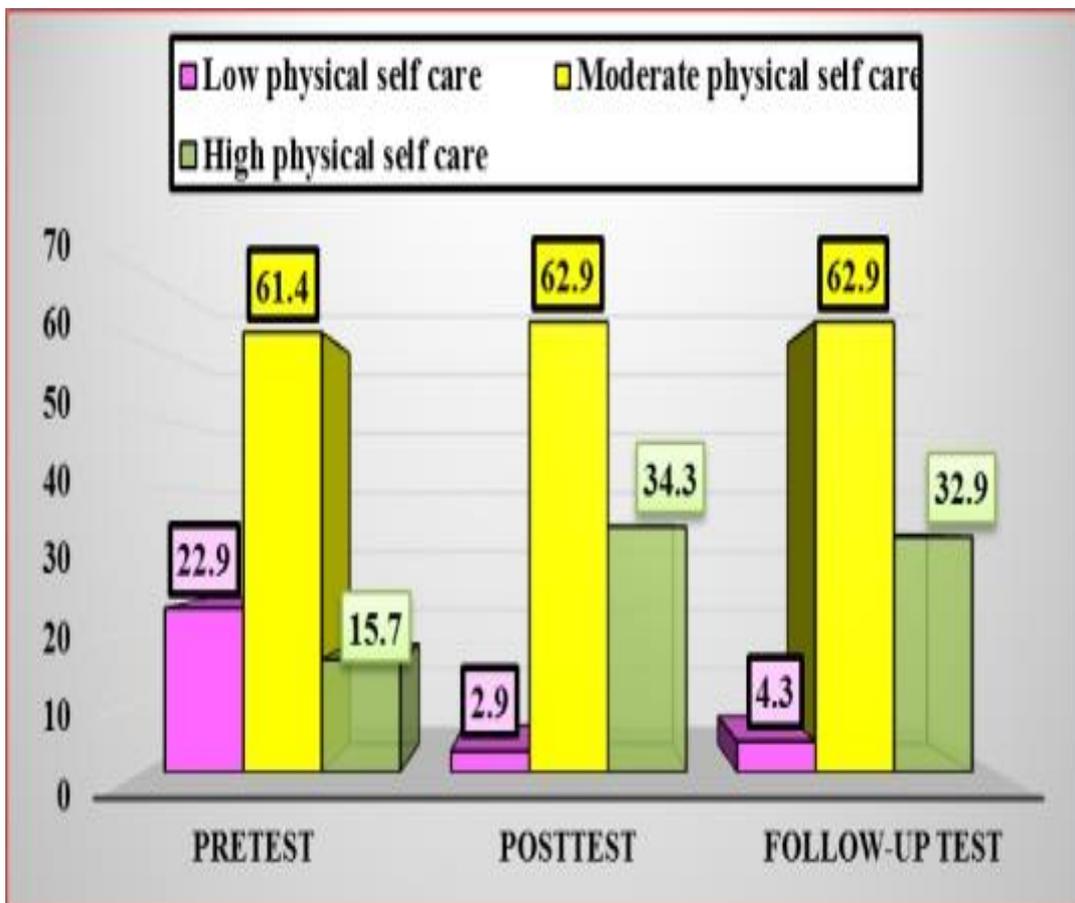
**Table (8): Descriptive statistics of the eight dimensions of the physical self-care among studied thalassemic children on pre post and follow up tests.**

Total score of physical self-care dimensions		Mean	Std. Deviation	F test	P
Nutrition	Pretest	25.3	7.5	1.93	0.14
	Posttest	27.3	6.4		NS
	Follow-up test	27.3	6.4		
Clothes	Pretest	10.4	3.4	4.3	< 0.01
	Posttest	11.8	3.0		S
	Follow-up test	11.6	2.8		
Dental care	Pretest	4.2	0.8	0.54	< 0.03
	Posttest	4.8	0.8		S
	Follow-up test	4.6	0.8		
Personal hygiene	Pretest	9.0	3.0	1.65	= 0.19
	Posttest	9.9	2.8		NS
	Follow-up test	9.7	2.7		
Sleep	Pretest	9.2	1.6	0.04	= 0.96
	Posttest	9.2	1.8		NS
	Follow-up test	9.2	1.8		
Exercise and sports	Pretest	7.4	1.8	0.65	= 0.52
	Posttest	7.7	1.5		NS
	Follow-up test	7.7	1.5		
Medication	Pretest	10.2	1.7	2.28	< 0.03
	Posttest	10.8	1.5		S
	Follow-up test	10.7	1.5		
Avoiding infection	Pretest	11.4	4.4	2.9	< 0.04
	Posttest	14.9	3.8		S
	Follow-up test	14.6	3.6		

*Effect of Self -Determination Theory Based Intervention on Self- Care Among School Age Children with Thalassaemia*

**Table (9):** levels of physical self-care among studied children on pre, post and follow up tests.

levels of physical self-care	Pretest		Posttest (after 30 days)		Follow- up Test		*Test of Sig.	P value
	N0 70	%	N0 70	%	N0 70	%		
Low physical self-care (45 - 81)	16	22.9	2	2.9	3	4.3	$\chi^2=22.9$	P < 0.0001 HS
Moderate physical self-care (82 - 101)	43	61.4	44	62.9	44	62.9		
High physical self-care (102 - 135)	11	15.7	24	34.3	23	32.9		
<b>Total</b>	<b>70</b>	<b>100.0</b>	<b>70</b>	<b>100</b>	<b>70</b>	<b>100</b>		
X± SD	88.9±14.1		95.6±11.3		94.9±11.3		F test=9.5	P3 < 0.003 HS
	t1=12.6		P1< 0.0001 HS		t2=10.2 P2 = 0.06 NS			



**Fig.1:** Levels of physical self-care among studied children on pre, post, and follow up tests.

**Effect of Self -Determination Theory Based Intervention on Self- Care Among School Age Children with Thalassaemia**

**Table (10): Levels of self-care dimensions among studied children on pre, post and follow up tests**

Levels of Self-care dimensions	Pretest		Posttest (after 30 days)		Follow –up Test		*Test of Sig.	P value
	No 70	%	No 70	%	No 70	%		
<b>Psychological self-care :</b>								
Low Psychological self-care (9 - 16)	27	38.6	11	15.7	11	15.7	$\chi^2 = 15.1$	<0.004 HS
Moderate Psychological self-care (17 - 20)	35	50	42	60	42	60		
High Psychological self-care(21 - 27)	8	11.4	17	24.3	17	24.3		
<b>Social self-care</b>								
Low social self-care (4 - 7)	25	35.7	17	24.3	17	24.3	$\chi^2 = 4.5$	0.33 NS
Moderate social self-care (8 - 9)	17	24.3	26	37.1	26	37.1		
High social self-care (10 - 12)	28	40	27	38.6	27	38.6		
<b>School self-care</b>								
Low school self-care (6 - 11)	31	44.3	16	22.9	16	22.9	$\chi^2 = 11.7$	<0.02 S
Moderate school self-care (12 - 14)	31	44.3	46	65.7	48	68.5		
High school self-care (15 - 18)	8	11.4	8	11.4	6	8.6		
<b>Total</b>	70	100	70	100	70	100		
<b>Mean± SD</b>	88.9±14.1		95.6±11.3		94.9±11.3		F test=9.5	P3<0.003 HS
<b>P value</b>	t <sub>1</sub> =12.6 P1<0.0001HS				t <sub>2</sub> =10.2 P <sub>2</sub> =.06 Ns			

**Discussion**

Thalassemia is a chronic disease that has a significant impact on the health of children. It necessitates regular medical care and usage of medications on a regular basis (Elsoudy et al., 2022). Thalassaemia is an inherited disease, meaning that at least one of the parents must be a carrier. It is a group of hemoglobinopathies in which the normal ratio of alpha to beta globin production is disrupted. This abnormal alpha to beta chain ratio causes the unpaired chains to precipitate, leading to destruction of red blood cell precursors in the bone marrow (ineffective erythropoiesis) and in the circulation (hemolysis). Children with thalassaemia have variable degrees of anemia and extra-medullary

hematopoiesis, which in turn can cause bone changes, impaired growth, and iron overload (Benz et al., 2022).

Thalassaemia and its complications affect self-care and quality of life of those children. Therefore, nursing interventions by nurses as essential careers are important (Madmoli et al., 2019).

Implementation of self- determination theory would significantly improve children’s quality of life and Self-care to promote their health and welfare to make their lives better (Ryan & Deci, 2017)

The current study hypothesized that Children with thalassaemia who receive the self-determination theory based intervention will have higher level of

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

knowledge, autonomy, relatedness and competency on posttest than pretest. Also, Children with thalassemia who receive the self-determination theory based intervention will have better self-care practices and higher quality of life dimensions on posttest than pretest.

In relation to hypothesis one: Children with thalassemia who receive the self-determination theory based intervention will have higher level of knowledge on posttest than pretest. The present study illustrated children's knowledge about thalassemia on pre, post and follow-up tests. The study revealed that the highest level of children's knowledge was on posttest ( $3.6 \pm 1.1$ ). From the researcher's perspective, this could be attributed to the positive effect of self-determination theory implementation. Also, children were enthusiastic to learn more about thalassemia.

This result was consistent with Meah 2021 et al., in their study about "Assessment of Awareness Among Parents of Children with Thalassemia Major in Bangladesh" who stated that the awareness and knowledge among parents and children with thalassemia were insufficient. They have inadequate knowledge regarding the disease, safe blood transfusion and treatments of associated complications. Also, this result came in agreement with Mohamed et al., (2021) in their study about "Effect of Empowerment Program on Self-efficacy among Children with Thalassemia." They found that all children had unsatisfactory knowledge about thalassemia before the program implementation, and significant improvement in knowledge of children detected immediate post and one month after the empowerment program.

In addition, the finding of present study was on the same line with

Zaghamir et al., (2019) in their study about "Assessment of Thalassemic Children Knowledge about Thalassemia and Iron Chelation Therapy". They concluded that there is an improvement in the children's knowledge after implementing educational training programs. This can be interpreted that nursing educational program was effective in improving children's knowledge.

Besides, this finding was consistent with Biswas et al., (2018) in their study about "Knowledge of the caregivers of thalassemic children regarding thalassemia: A cross-sectional study in a tertiary care health facility of eastern India" who concluded that Children and caregivers' knowledge regarding thalassemia was not at all satisfactory.

In the same line, this result agreed with Atshan, & Aziz (2022) in their study about "Impact of an educational program on knowledge about chelation therapy & nutrition of children with beta thalassemia major". They showed that education program was highly effective on improving knowledge of children with beta thalassemia major.

In relation to hypothesis two: Children with thalassemia who receive the self-determination theory based intervention will have higher level of autonomy, relatedness and competency on posttest than pretest. The findings of the current study clarified that there was a significant improvement in the children's autonomy, relatedness and competency. From the researcher's perspective, this could be attributed to the clarity and simplicity of the methods of teaching (oral presentations, group discussion, smart phone, communication board, feedbacks and explanatory booklets) that were used in sessions which in turn helped children to acquire and improve their knowledge, autonomy, relatedness and competency. Besides, the utilized communication techniques

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

(e.g. good listening, feedback and two-way communications) could be effective.

Regarding autonomy, the present study concluded that there was significant improvement in children's autonomy score on posttest than on pretest. This result was in line with Nourbakhsh et al., (2021) in their study about "The Association between Behavioral Problems with Self-Esteem and Self-Concept in Pediatric Patients with Thalassemia". They found that children had poor self-esteem and low autonomy.

In addition, these results came in agreement with Tomaj et al., (2016) who conducted a study about "The Effects of Group Play Therapy on Self-Concept Among 7 to 11 Year-Old Children Suffering From Thalassemia Major". They showed that the mean self-concept and autonomy score was significantly higher at the second point in time compared to the baseline. They also showed that group play therapy improved self-concept and autonomy in those children.

Regarding relatedness, the present study concluded that there was significant improvement in children's relatedness score on posttest than on pretest. These results came in agreement with Stanton et al., (2020) in their study about "Self-determination theory in acute child and adolescent mental health inpatient care. A qualitative exploratory study". They showed that Engaging young people in activities with a focus on relatedness, autonomy and competence had therapeutic benefits. Connection with staff and peer interaction improve children's relatedness and enhance their safety.

Also, This result was consistent with El zaree et al., (2018) in their study about "Adaptive Functioning and Psychosocial Problems in Children with Beta Thalassemia Major ". They

found that thalassemic children had a relatively mild affection for adaptive and psychosocial functioning that can be explained by social and medical support they receive, which may increase their competence and psychological wellbeing.

Moreover, this result came in agreement with Keshvari et al.,(2013) in their study about " Relation between Children's Well-Being and Family Function in Children with Thalassemia Major in Isfahan ". They concluded that the children with thalassemia had low relatedness, and there is a direct relationship between family functioning and emotional well-being of children with thalassemia.

Regarding competency, the present study concluded that there was significant improvement in children's competency score on posttest than on pretest. These results came in agreement with Feng et al., (2022) in their study about "Effect of Self-Determination Theory on Knowledge, Treatment Adherence, and Self-Management of Patients with Maintenance Hemodialysis ".They showed that Self-determination theory management is effective in improving hemodialysis-related treatment compliance, self-management ,competency level and quality of life.

Also, these results came in agreement with Baghersalimi et al., (2021) in their study about "Evaluation of Self-efficacy in Children and Adolescents With Thalassemia Major" they showed that the rate of self-efficacy and competency in children with thalassemia was moderate, and the allocation of a specific ward, easy access to health care staff, and social support for children may seem to justify the moderate to good self-efficacy.

Besides, this finding was in line with Wongnonglaeng et al., (2021) in their study about " The effects of health

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

program based on Bandura's theory using gamification on perceived self-efficacy in health care of school-age children with thalassemia " They showed that the mean score of perceived self-efficacy in health care of school-age children with thalassemia in the experimental group at the end of the intervention and at 1 week post intervention was significantly higher than that before the intervention and in the control group.

This finding was also in conformity with Elsoudy et al., (2022) in their study about "Original Article Compliance of Children with Thalassemia to Their Therapeutic Regimen." They concluded that the majority of children with thalassemia were able to comply with their therapeutic regimen.

Furthermore, this finding was in line with Hamamy, & Al-Allawi (2013) who conducted a study about "Epidemiological profile of common haemoglobinopathies in Arab countries" they showed that school-age children had more increased abilities to complete their health care tasks such as filling prescription or recognize symptoms of illness.

Meanwhile, this finding was in line with Mazzone et al., (2019) who conducted a study about " Emotional impact in  $\beta$ -thalassaemia major children following cognitive-behavioral family therapy and quality of life of caregiving mothers." they showed that children had more increased abilities to compliance with their therapy and treatment after implementation of cognitive-behavioral family therapy.

In the same context, this finding was in line with Moghadam et al., (2016) who conducted a study about " Effects of Home-Care Training on The Self-Efficacy of Patients With Beta Thalassemia Major" they showed that there were significant improvement in

self-efficacy and competency after implementation of home-care training program.

In relation to hypothesis three: Children with thalassemia who receive the self-determination theory based intervention will have higher level of self-care practices on posttest than pretest. The present study illustrated that there was significant improvement in children's level of self-care (physical, psychological, social and school functioning) on posttest than on pretest. From the researcher's perspective, this could be attributed to the positive effect of self-determination theory implementation. Also, children were enthusiastic to learn more about their self-care. These results came in agreement with Williams et al., (2014) in their study about "Testing a Self-Determination Theory Process Model for promoting glycemic control through diabetes self-management". They showed that implementation of self-determination theory improved self-management behaviors and self-care that causes change in perceived competence and glycemic control.

Also, these results came in agreement with Kaur et al., (2015) in their study about "Effectiveness of Cartoon Picture Book On Self-Care Behavior Of Children Between 4-10 Years Of Age Suffering From Thalassemia." They showed that learning program resulted in a statistically significant change in self-care behavior of children suffering from thalassemia after intervention.

Besides, these results came in agreement with Masinaeinezhad et al., (2018) in their study about "The effect of self-care education based on Orem's model on self-efficacy of patients with beta thalassemia ". They showed that there were significant improvements in the level of self-care behaviors after the mobile-phone mediated education.

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

In addition, these results came in agreement with Gharaati, & Aghamolaei, (2019) in their study about "Effect of a mobile-phone mediated based education on self-care behaviors of patients with thalassemia major". They showed that mobile-phone mediated education had a positive effect on self-care behaviors of the patients with thalassemia major. Regarding physical functioning the findings of the current study showed improvement in children's level of physical self-care immediately post health teaching implementation. This result was consistent with Masinaienejad et al., (2019) in their study about "The Impact of Self-care Education Based on Orem's Model on Self-care Behaviors of Patients with  $\beta$ -Thalassemia Major: A Clinical Trial." They concluded that administering the self-care program had a significant effect in improving three aspects of self-care, including mental health, physical activities, and therapeutic measures in patients with major  $\beta$ -thalassemia.

Besides, this result agreed with Kshaish et al., (2017) in their study about "Assessment of Daily Living Activities of Thalassemic School Age Children at Thalassemia Center in Ebn- Albaldy Maternal and Child Hospital at Baghdad City." They reported that the activities of daily living of the thalassemic school age children is at moderate level.

Regarding nutrition the findings of the current study showed improvement in children's nutritional level and compliance to diet immediately post health teaching implementation. This result was consistent with Molazem et al., (2016) in their study about "The Effects of Nutrition, Exercise, and a Praying Program on Reducing Iron Overload in Patients With Beta-Thalassemia Major: A Randomized Clinical Trial " They reported that The

planned educational program could be used to reduce iron overload and ultimately improve the patients' health status.

In addition, this result agreed with Shahraki et al., (2020) in their study about "Impact of Pender model training program on lifestyle of parents of children with Thalassemia Major". They showed that Training program enhances the lifestyle of children with thalassemia major as nutrition, and physical activity.

Besides, this result agreed with Sreenivasan et al., (2017) in their study about "Impact of diet counseling in thalassemic children and its response on nutritional status ". They showed that diet counseling program help improved nutritional status in children with thalassemia, and they need continuous dietary assessment and counseling to attain a balanced nutrition.

Regarding personal hygiene and preventing infection the findings of the current study showed increasing level of awareness of children regarding personal hygiene and preventing infection post implementation. This could be attributed to effect of educational program based on self-determination theory. This result was consistent with Ntoumanis et al., (2021) in their study about "A meta-analysis of self-determination theory-informed intervention studies in the health domain: effects on motivation, health behavior, physical, and psychological health". They reported that SDT-informed interventions positively affect indices of health and causes positive changes in physical health behaviors as diet, hygiene and infection.

Regarding rest and sleep the findings of the current study showed increasing level of awareness of children regarding importance of regular sleeping pattern and improving sleep

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

quality post implementation. This could be related to adherence of children to educational instructions. This result was consistent with Campbell et al., (2015) in their study about "Examining the role of psychological need satisfaction in sleep: A Self-Determination Theory perspective". They showed that high psychological need satisfaction and implementation of self-determination theory is related to better sleep quality, quantity, and more daytime function.

Also, this result was consistent with Makaremnia et al., (2021) in their study about "Effects of a positive thinking program on hope and sleep quality in Iranian patients with thalassemia: a randomized clinical trial". They showed that training program on positive thinking improved hope and quality of sleep in patients with thalassemia

Regarding medication the findings of the current study showed improvement in children's compliance to therapy immediately post health teaching implementation. This could be attributed to nursing program was effective in improving children's adherence to therapy. This result was consistent with Williams et al., (2009) in their study about "Reducing the Health Risks of Diabetes: How Self-determination Theory May Help Improve Medication Adherence and Quality of Life". They reported that health care providers' support for patients' autonomy and competence around medication use and diabetes self-management affect positively on medication adherence among those patients.

Also, this result agreed with Elsoufy et al., (2021) in their study about "Compliance of Children with Thalassemia to Their Therapeutic Regimen." They reported that the majority of children with thalassemia were complying with their therapeutic

regimen after implementation of intervention.

In addition, this result agreed with Mostafa et al., (2014) in their study about "Factors affecting compliance plan of thalassemic children and their mothers in Outpatient Clinic at Zagazig University Hospitals". They showed that thalassemic children has poor commitment to therapeutic regimen and treatment adherence as a result of their poor knowledge that affect their physical self-care.

Also, this result agreed with Aziz et al., (2021) in their study about "Impact of Lifestyle Modification Module on Adherence to Therapeutic Regimen of Children and Adolescents with Beta Thalassemia Major". They showed that There were significant improvements of knowledge, adherence of the studied children to therapeutic regimen and physical activity post the lifestyle modification module application.

Besides, this result agreed with Aboeela et al., (2018) in their study about "Effect of multidimensional intervention on improving adherence of thalassemic children to iron chelation therapy". They showed that the multidimensional intervention improved thalassemic children's adherence to iron chelation therapy.

Regarding exercise and physical activity the findings of the current study showed improvement in children's level of physical activity post health teaching implementation. This can be interpreted that nursing educational program increased children's awareness about importance of exercise. This result was consistent with Ball et al., (2017) in their study about "Exploring the Relationship between Self-Determination Theory, Barriers to Exercise, and Physical Activity". They showed that motivation that is more self-regulated and intrinsically motivated could help

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

inspire individuals to engage in physical activity more frequently.

Also, this result was consistent Sebire et al., (2013) in their study about "Testing a self-determination theory model of children's physical activity motivation: a cross-sectional study". They showed that Psychological need satisfaction (in particular autonomy) was strongly associated with intrinsic motivation and increasing children's physical activity.

Besides, this result agreed with consistent Gariépy et al., (2010) in their study about "Reduced physical activity in adult and pediatric patients with thalassemia." They showed that thalassemic children are less physically active and have significantly reduced muscle mass compared to others and their physical activity level improved after teaching program.

Meanwhile, this result agreed with Ismail et al., (2018) in their study about "Evaluation of health-related quality of life and muscular strength in children with beta thalassemia major " they showed that thalassemia has a negative impact on exercise level and muscle strength of children in different age group. Regular training program help improve activity level in those children.

Regarding emotional functioning the findings of the current study showed improvement in children's level of emotional self-care immediately post health teaching implementation. This could be attributed to effectiveness of health education sessions. This result was consistent with Mohn et al., (2017) in their study about "The effect of guided self-determination on self-management in persons with type 1 diabetes mellitus and HbA1c  $\geq 64$  mmol/mol: a group-based randomized controlled trial". They concluded that self-determination intervention improved Psychological outcomes especially distress.

Also, this result was consistent with Behdani et al., (2015) in their study about "Psychological Aspects in Children and Adolescents with Major Thalassemia: A Case-Control Study." They concluded that there are significant changes in depression, anxiety, and behavioral screening between children with thalassemia. They also showed that appropriate treatment and counseling procedures in addition to specific treatment of thalassemia help reducing these psychological aspects of the disease.

Also, this result was consistent with Hassan & Elmwaife (2016) in their study about "Study of the Health Instructions Effect on Quality of Life and Psychological Problems among Children with Thalassemia." They concluded that health instructions for children with thalassemia and their parents had significant effect in improvement of children psychological problems.

Besides, this result was consistent with Mazzone et al., (2019) in their study about "Emotional impact in  $\beta$ -thalassaemia major children following cognitive-behavioral family therapy and quality of life of caregiving mothers". They concluded that cognitive-behavioral family therapy improved emotional status in those children, while they continue to show an emotional burden.

In addition, this result was consistent with Ali et al., (2018) in their study about "Coping strategies among children with thalassemia". They concluded that thalassemic children had psychological disorders, and the use of coping strategies was effective in building the general wellbeing of those children.

Regarding social functioning the findings of the current study showed improvement in children's level of social self-care post health teaching implementation. This result was

consistent with Akter et al., (2020) in their study about "Lived Experience of Thalassemic Children in Bangladesh". They showed that thalassemia affected negatively on several areas of health of these children including social areas, and reducing these problems requires comprehensive constant support and surveying health and medical status of these children to promote care and decrease their suffering.

Regarding school functioning the findings of the current study showed improvement in children's level of school self-care post health teaching implementation. This result was consistent with Saha et al., (2016) in their study about "School Functioning Activity of Bengali Thalassemic Children Attending a Tertiary Care Hospital of Eastern India". They concluded that School functioning activity of thalassemic children is generally poor, but counseling of parents and families improved their performance.

In addition, this result agreed with Kshaish & Aziz (2020) who conducted a study about "Assessment of Daily Living Activities of Thalassemic School Age Children at Thalassemia Center in Ebn- Albalady Maternal and Child Hospital at Baghdad City". They concluded that there is a low level (1.79) towards the activities of daily living of the thalassemic school age children.

Also, this result agreed with Greco et al., (2022) in their study about "Social Impact and Quality of Life of Patients with  $\beta$ -Thalassaemia: A Systematic Review". They showed that programs by healthcare providers, counselors, and education authorities provide psychosocial support, and improve academic performance in children with thalassemia.

Besides, this result agreed with Dayasiri, & Mudiyanse (2020) in their study about "Effectiveness of training

parents of beta thalassemia patients in improving medical student-patient communication: a developing country-perspective". They showed that Training of parents significantly improved medical students' commitment to learning and obtaining feedback from parents.

### **Conclusion**

Based on the finding of the present study, the following is concluded:

- Children with thalassemia who received self-care determination theory based intervention had higher level of knowledge about thalassemia on posttest than pretest. Also, Children with thalassemia who received self-care determination theory based intervention had higher level of autonomy, relatedness and satisfaction on posttest than pretest. Meanwhile; they had higher level of practice about self-care on posttest than pretest.

### **Recommendations**

In the light of the findings obtained from the current study and its conclusion, the following recommendations are suggested:

- 1) Self-determination theory based intervention about thalassemia should be designed and implemented in pediatric thalassemia units to improve children's knowledge and practices on the basis of their actual needs.
- 2) Self-determination theory based intervention about thalassemia should be designed and implemented in pediatric thalassemia units to improve parent's knowledge and practices to provide optimum care to children.

## **B. Recommendations for future**

### **Research: -**

Further studies should be applied on a larger sample to determine the effect of self-determination theory based intervention to ensure the generalizability of results.

### **References**

- Aboeela, E., El-Dakhkhny, A., Hesham, M., & El-Abdeen, K. Z. (2018). Effect of multidimensional intervention on improving adherence of thalassemic children to iron chelation therapy. *Zagazig Nursing Journal*, 14(2), 153-166.
- Ali, A., El-Bilsha, M., & Mohamed, A. (2018). Coping strategies among children with thalassemia. *J Nurs Health Sci*, 7(2), 50-58.
- Ansteenkiste, M., Delesie, L. M., Mariman, A. N., Soenens, B., Tobback, E., ... & Vogelaers, D. P. (2015). Examining the role of psychological need satisfaction in sleep: A Self-Determination Theory perspective. *Personality and individual differences*, 77, 199-204.
- Atshan, R. S., & Aziz, A. R. (2022). Effectiveness of an Educational Program on Knowledge about Home Health Care Management to Children with Beta Thalassemia-Major at Thalassemia Center in Al-Zahra Teaching Hospital for Maternity and Children in Al-Najaf City. *Pakistan Journal of Medical & Health Sciences*, 16(03), 931-931.
- Aziz, R. A., Al Rafay, S., Matter, R. M., & El Hassan, S. (2021). Impact of Lifestyle Modification Module on Adherence to Therapeutic Regimen of Children and Adolescents with Beta Thalassemia Major. *Medico-Legal Update*, 21(2).
- Baghersalimi, A., Darbandi, B., Kazemnezhad Leyli, E., Kamran Mavardiani, Z., Ahmad Sharbafi, M., & Rezasefat Balesbaneh, A. (2021). Evaluation of self-efficacy in children and adolescents with thalassemia major. *Journal of Pediatric Hematology/Oncology*, 43(6), e754-e758.
- Ball, J. W., Bice, M. R., & Maljak, K. A. (2017). Exploring the Relationship between Self-Determination Theory, Barriers to Exercise, and Physical Activity. *Health Educator*, 49(1).
- Benz Jr, E. J., & A Williams, G. C., McGregor, H. A., Zeldman, A., Freedman, Z. R., & Deci, E. L. (2014). Testing a self-determination theory process model for promoting glycemic control through diabetes self-management. *Health Psychology*, 23(1), 58.
- Biswas A., Shawky R. and Kamal T. (2019): Thalassemia intermedia: An overview, *Egyptian journal of medical human genetics science direct*:13(3) P. 245- 255.
- Campbell, R., V Behdani, F., Badiie, Z., Hebrani, P., Moharrerri, F., Badiie, A., Hajivosugh, N., & Akhavanrezayat, A. (2015). Psychological aspects in children and adolescents with major thalassemia: A case-control study. *Iranian journal of pediatrics*, 25(3).
- Dayasiri, K., & Mudiyanse, R. (2020). Effectiveness of training parents of beta thalassemia patients in improving medical student-patient communication: a developing country-perspective. *Sri Lanka Journal of Child Health*, 49(4), 369-374.

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

- Eliezer A., Rachmilewitz . and Giardia P. (2016) : How I treat thalassemia: [www.bloodjournal.org](http://www.bloodjournal.org) :61(3); P. 3479.
- Elsoudy, S. F., Madinay, N., & Yonis Mahrous, E. S. (2022). Compliance of Children with Thalassemia to Their Therapeutic Regimen. *International Egyptian Journal of Nursing Sciences and Research*, 2(2), 168-182.
- Elsoudy, S. F., Madinay, N., & Yonis Mahrous, E. S. (2022). Compliance of Children with Thalassemia to Their Therapeutic Regimen. *International Egyptian Journal of Nursing Sciences and Research*, 2(2), 168-182.
- Elzaree, F. A., Shehata, M. A., El Wakeel, M. A., El-Alameey, I. R., AbuShady, M. M., & Helal, S. I. (2018). Adaptive functioning and psychosocial problems in children with beta thalassemia major. *Open Access Macedonian Journal of Medical Sciences*, 6(12), 2337.
- Gariépy, C., Lal, A., & Fung, E. (2010). Reduced physical activity in adult and pediatric patients with thalassemia. *Blood*, 116(21), 5174.
- Gharaati, F., & Aghamolaei, T. (2019). Effect of a mobile-phone mediated based education on self-care behaviors of patients with thalassemia major. *Journal of Caring Sciences*, 8(3), 149.
- Greco, F., Franca, M.(2022). Social Impact and Quality of Life of Patients with
- Hamamy, H. A., & Al-Allawi, N. A. (2013). Epidemiological profile of common haemoglobinopathies in Arab countries. *Journal of community genetics*, 4(2), 147-167.
- Hassan, S. M. E., & Elmwaife S. H. I. (2016). Study of the health instructions effect on quality of life and psychological problems among children with thalassemia. *International Journal of Studies in Nursing*, 1(1), 16.
- Hock, R., Kinsman, A., & Ortaglia, A. (2015). Examining treatment adherence among parents of children with thalassemia. *Disability and health journal*, 8(3), 407-413.
- Kadhim, K. A., Baldawi, K. H., & Lami, F. H. (2019). Prevalence, incidence, trend, and complications of thalassemia in Iraq. *Hemoglobin*, 41(3), 164-168.
- Kahouei M., Kazemzadeh F., Zadeh J. and Ahmadi Z. (2016): Hierarchy of Iranian parents information needs and social seeking behavior of infants suffering blood disease: the social sciences:31(6); P. 336.
- Kaur, R., Kaur, R., Kaur, S., Marwaha, L. R., & Bansal, D. (2015). Effectiveness of Cartoon Picture Book on self-care behavior of children between 4-10 years of age suffering from Thalassemia. *Nursing & Midwifery Research Journal*, 11(4), 185-197.
- Kshaish, R. H., & Aziz, A. R. (2017). Assessment of Daily Living Activities of Thalassemic School Age Children at Thalassemia Center in Ebn-Albaldy Maternal and Child Hospital at Baghdad City.
- Kshaish, R. H., & Aziz, A. R. (2017). Assessment of Daily Living Activities of Thalassemic School Age Children at Thalassemia Center in Ebn-Albaldy Maternal and Child Hospital at Baghdad City.
- Madmoli, Y., Salimi, M., Madmoli, M., Maraghi, E., Pelarak, F., Korkini, N., & Mashalchi, H. (2019). The effect of orem self-

- care model on health-related quality of life of patients with thalassemia major. *Journal of Research in Medical and Dental Science*, 7(2), 170-176.
- Makaremnia, S., Dehghan Manshadi, M., & Khademian, Z. (2021). Effects of a positive thinking program on hope and sleep quality in Iranian patients with thalassemia: a randomized clinical trial. *BMC psychology*, 9(1), 1-10.
- Masinaeinezhad, N., mohammad, A., Bonjar, A. K., & Allahyari, J. (2018). The effect of self-care education based on Orem's model on self-efficacy of patients with beta thalassemia major. *La Prensa Medica Argentina*, 104(4), 1-4.
- Masinaeinezhad, N., mohammad, A., Bonjar, A. K., & Allahyari, J. (2018). The effect of self-care education based on Orem's model on self-efficacy of patients with beta thalassemia major. *La Prensa Medica Argentina*, 104(4), 1-4.
- Mazzone, L., Battaglia, L., Andreozzi, F., Romeo, M. A., & Mazzone, D. (2019). Emotional impact in  $\beta$ -thalassaemia major children following cognitive-behavioural family therapy and quality of life of caregiving mothers. *Clinical practice and epidemiology in mental health*, 5(1), 1-6.
- Mazzone, L., Battaglia, L., Andreozzi, F., Romeo, M. A., & Mazzone, D. (2019). Emotional impact in  $\beta$ -thalassaemia major children following cognitive-behavioural family therapy and quality of life of caregiving mothers. *Clinical practice and epidemiology in mental health*, 5(1), 1-6.
- Moghadam, M. P., Nourisancho, H., Shahdadi, H., Shahraki, S., Azarkish, B., & Balouchi, A. (2016). Effects of home-care training on the self-efficacy of patients with beta thalassemia major. *Materia socio-medica*, 28(5), 357.
- Mohn, J., Graue, M., Assmus, J., Zoffmann, V., Thordarson, H., Peyrot, M., & Rokne, B. (2017). The effect of guided self-determination on self-management in persons with type 1 diabetes mellitus and HbA1c  $\geq$  64 mmol/mol: a group-based randomised controlled trial. *Bmj Open*, 7(6), e013295.
- Molazem, Z., Noormohammadi, R., Dokouhaki, R., Zakerinia, M., & Bagheri, Z. (2016). The Effects of Nutrition, Exercise, and a Praying Program on Reducing Iron Overload in Patients With Beta-Thalassemia Major: A Randomized Clinical Trial. *Iranian Journal of Pediatrics*, 26(5).
- Mostafa, S., & Ab Elaziz, M. (2014). Factors affecting compliance plan of thalassaemic children and their mothers in Outpatient Clinic at Zagazig University Hospitals. *Journal of Biology, Agriculture and Healthcare*, 4(3), 42-46.
- Naggrawal A., Arorams A., Dewan P. and Harish K. (2011): *Essential pediatric nursing: 3rd*, India, CBS publishers  $\alpha$ , distributors PVT. LTD, P.P; 447, 448,449, 450, 451.
- Navaneetha, K., S., Shaji, G., Ravalya, P., & Nazi, S.K. (2013). Management of thalassemia. *International research journal of pharmacy*, 4(10), 1-3.
- ngelucci, E. Diagnosis of thalassemia (adults and children), 2022. Available at: <https://www.wolterskluwer.com/en/know/clinical-effectiveness-terms>
- Nourbakhsh, S. M. K., Atamanesh, M., Effatpanah, M., Salehi, M., &

*Effect of Self-Determination Theory Based Intervention on Self-Care Among School Age Children with Thalassemia*

- Heidari, M. (2021). The Association between Behavioral Problems with Self-Esteem and Self-Concept in Pediatric Patients with Thalassemia. *Iranian Journal of Psychiatry*, 16(1), 36.
- Ntoumanis, N., Ng, J. Y., Prestwich, A., Quested, E., Hancox, J. E., Thøgersen-Ntoumani, C., ... & Williams, G. C. (2021). A meta-analysis of self-determination theory-informed intervention studies in the health domain: effects on motivation, health behavior, physical, and psychological health. *Health Psychology Review*, 15(2), 214-244.
- Patric, K. (2010). Quality of life in chronic disease patients. *Health psychology research*, 1(3).
- Potts N. and Mandleco B. (2012): Pediatric nursing caring for children and their families, 3rd ed. Australia: Delmar:12(1); P. 926.927.928.
- Ragb, S. M., Elrahim, M. A., El Fotoh, W. M., & Ibrahim, R. A. (2021). Screening of  $\beta$ -thalassemia carriers in high school students in Shebin El-Kom, Menoufia Governorate. *Menoufia Medical Journal*, 34(1), 237.
- Raza S., Ishfaq K. & Fazal H. (2015): social impact of thalassemia major on patients families: 2(3); P.413.
- Safizadeh H., Farahmandinia Z., Soltaninejad S., Pourdanghan N. and Araste M. (2012): Quality of life in patient with thalassemia major and intermedia in kerman-iran : *Mediterranean journal of hematology and infectious disease*: 4(1) ; P.4.5.
- Saha, R., Misra, R., & Saha, I. (2016). School functioning activity of Bengali thalassemic children attending a tertiary care hospital of eastern India. *International Journal of Travel Medicine and Global Health*, 4(3), 82-87.
- Sebire, S., Jago, R., Fox, K., Edwards, M., & Thompson, J. (2013). Testing a self-determination theory model of children's physical activity motivation: a cross-sectional study. *International Journal of Behavioral Nutrition and Physical Activity*, 10(1), 111.
- Shahraki, M., Firouzkhouchi, M., Abdollahimohammad, A., & Naderifar, M. (2020). Impact of Pender model training program on lifestyle of parents of children with Thalassemia Major. *Medical Science*, 24(101), 243-248.
- Shanshory M., Hagag., sheble., AbdElhamed., Abd El- Bar., Al-Tonbary., Mansour., Hassan., Hamdy., Alfy., Sherief. and Sharaf, (2021) : spectrum of beta globin gene mutations in Egyptian children with B-thalassemia: *Mediterranean journal of hematology and infectious disease*:11(8); P. 2.
- Williams, G. C., McGregor, H. A., Zeldman, A., Freedman, Z. R., & Deci, E. L. (2014). Testing a self-determination theory process model for promoting glycemic control through diabetes self-management. *Health Psychology*, 23(1), 58.
- Wilson D. and Hockenberry M. (2011): *Nursing care of infants and children*, 9th, china, Elsevier; P.1436, 1437, 1438, 1439.
- $\beta$ -Thalassaemia: A Systematic Review. Available <https://doi.org/10.33590/emjhematol/22-00041>